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Caring for sons and daughters with disabilities across the life course: Hearing the data

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Sons and Daughters with Disabilities:
Childcare issues across the lifespan.

Hearing the data

Karola Dillenburg & Lyn McKerr

November 2011

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CONTENTS	Page
Foreword	vi
Executive Summary	vii
Section 1: Introduction	1
1.1 Literature review	2
1.1.1 <i>Families across the lifespan</i>	2
1.1.2 <i>Disability and care giving</i>	4
1.1.3 <i>Care within the family</i>	6
1.1.4 <i>Care outside the family</i>	7
1.2. Policy and legal context	8
1.3 Ethical approval	11
Section 2: Methodology	12
2.1 Participants	12
2.1.1 <i>Parent/Caregivers- individual interviews</i>	12
2.1.2 <i>Parent/care givers- focus group</i>	13
2.1.3 <i>Service users-focus group</i>	14
2.1.4 <i>Service Providers - individual interviews</i>	15
2.2 Research tools	16
2.2.1. <i>Parent/Caregiver interview</i>	16
2.2.2 <i>Parent/caregiver and service user focus groups</i>	17
2.2.3. <i>Service provider interview</i>	17
2.3 Research procedure	17
2.3.1 <i>Literature review</i>	18
2.3.2 <i>Pilot study</i>	18
2.3.3 <i>Individual interviews</i>	18
2.3.4 <i>Focus groups</i>	19
2.4 Data analysis	19
Section 3. Parent/caregiver individual interview results	21
3.1 Home and Family Life	21
3.1.1 <i>Housing circumstances</i>	22
3.2 Emotional and physical health issues	23
3.2.1 <i>Emotional issues within the immediate family</i>	23
3.2.2 <i>Personal health problems</i>	26
3.2.3 <i>Emotional and physical health issues for sons and daughters with disabilities</i>	26
3.3 Care within the family	30
3.3.1 <i>Care arrangements within the family: everyday living</i>	31
3.3.1.1. <i>Going out with family members</i>	34
3.3.2 <i>Care arrangements within the extended family</i>	35

3.4 Care arrangements outside the family	36
<i>3.4.1 Friends and neighbourhood</i>	36
<i>3.4.2 Accessing services and support</i>	37
<i>3.4.2.1 Services and support from Health and Social care professionals</i>	37
<i>3.4.2.2 Holidays and using respite/short breaks services</i>	39
<i>3.4.2.3 Peer support and caregiver organisations</i>	41
<i>3.4.2.4 Social opportunities for sons and daughters</i>	42
<i>3.4.3 Education, work and training for sons and daughters</i>	43
<i>3.4.3.1 Parental satisfaction with placements</i>	45
3.5 Health and social care: service evaluation	47
<i>3.5.1 The ideal care and support system: the parent's view</i>	50
3.6 Family finances	52
3.7 The future	55
<i>3.7.1 Changing attitudes</i>	55
<i>3.7.2 Growing older</i>	56
<i>3.7.3 Making future plans</i>	57
 Section 4. Parent/caregivers: Focus group findings	 59
4.1 Access to services and support	59
4.2 Support within the extended family	61
4.3 Services and support outside the family	61
<i>4.3.1 Interventions following diagnosis</i>	62
<i>4.3.2 Accessing pre-school services</i>	65
<i>4.3.3 Services provided through schools</i>	65
<i>4.3.4 Short breaks and respite services</i>	66
4.4 Planning for the future	67
 Section 5. Young adult service users: Focus group findings	 69
5.1 Home and family life	69
5.2 Services and support outside the family	70
<i>5.2.1 Short breaks and holidays</i>	70
<i>5.2.2 Clubs and other social organisations</i>	71
<i>5.2.3 Work, college and day-centres</i>	73
5.3 Young adults planning for the future	75
 Section 6. Service providers: Individual interview findings	 76
6.1 Service profiles	76
<i>6.1.1 Funding of services</i>	77
<i>6.1.2 Access to services</i>	77
<i>6.1.3 Staff training</i>	78
6.2 Services provided	78
<i>6.2.1 Services outside the family home</i>	79
<i>6.2.2 Children's and adult services</i>	80
6.3 Service evaluation	82

<i>6.3.1 Improving the services: provider's perspectives</i>	84
Section 7: Recommendations from parent/ caregivers	87
7.1 Recommendations to other parent/caregivers	87
<i>7.1.2 Peer support</i>	87
<i>7.1.3 Determination, knowledge, and getting things right from the start</i>	87
<i>7.1.4 Valuing family life</i>	88
<i>7.1.5 Good relationships with professionals</i>	89
7.2 Recommendations for service providers and policy makers	89
<i>7.2.1 Joined-up service provision and valuing caregiver experience</i>	89
<i>7.2.2 Information sharing</i>	91
<i>7.2.3 Awareness and training in disability issues</i>	91
<i>7.2.4 Flexible thinking around service and policy decisions</i>	91
Section 8: Discussion, summary and key findings	93
8.1 Home and family life	93
8.2 Family health and wellbeing	94
<i>8.2.1 Parent/caregivers</i>	94
<i>8.2.2 Sons and daughters</i>	94
8.3 Financial aspects of well-being	95
8.4 Care and support within the family	96
8.5 Care and support outside the family	97
8.6 Accessing services	98
<i>8.6.1 Specific issues for carers of young children</i>	98
<i>8.6.2 Specific issues for carers of older children and adults</i>	99
8.7 Evaluation of services	100
8.8 Social and life skills	101
8.9 Experiences and implications across the lifespan: the bigger picture	102
8.10 Accessing care outside the home	104
8.11 Conclusion: Policy and practice	106
Section 9: Recommendations to professionals and policy makers	108
References	111
Glossary of abbreviations	118
APPENDIX 1: Information and consent forms	119
APPENDIX 2: Interview and Focus Group Schedules	124
APPENDIX 3 Example of DLA letter	133

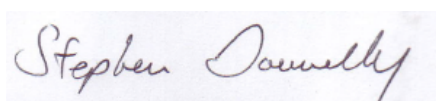
Foreword

The issue of caring across the lifespan has been given added importance due to the well-documented demographic trends that face many European and developing countries. The broader issues of age discrimination, the need for older people to remain in the workforce, the need to plan for the expected rise in the number of people suffering dementia and developments in telemedicine are all relevant to this report. It is a timely report, coming as it does at the time of the appointment of the first Older Persons Commissioner and the review of ‘Ageing in an Inclusive Society’.

The research strategy of the Office of the First Minister and deputy First Minister has, as one of its principal aims, the objective of giving a voice to the disadvantaged. This report supports that objective but does so in a way that highlights the connection between service provision and coordination and the impact of those services on family life.

By setting out some of the important actions that can support parents with caring responsibilities for children and young adults, and by linking service provision such as childcare for children with disabilities and professional development of staff working with individuals with disabilities across the lifespan, the report illustrates the need to consider families in terms of not just their current but also their future needs.

Perhaps the most engaging element of the report is the story as told by parents both young and old in their own words. Planning for the future is one of the key themes identified in the report. This is an important theme and one that any future development of strategy and policy in respect of older people will need to take into consideration. I am confident that in presenting this report it will form a valuable addition to the extant literature and a useful document for policy makers, practitioners and lobby groups.



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Executive summary

Nearly 200,000 unpaid caregivers in Northern Ireland save the taxpayer well over £4 billion per year (Carers NI, 2011). With 3.9% of school-aged children having a statement of special educational needs (Every School a Good School, 2009; Geraghty & Sinclair, 2007), and over 80% of persons with disabilities being cared for across their entire life course by their parent/caregivers (NHS Ealing, 2011), parenting a son/daughter with disabilities becomes a major issue across the lifespan. At the same time, the level of public investment in childcare is extremely poor in Northern Ireland when compared with England and Ireland (Fawcett, 2009).

The dearth of information on the supply, demand, and quality for childcare in general, and childcare for children with disabilities in particular, is matched by the growing concern about a rapid increase of an ageing population, especially with regard to ageing parents who care for their ageing sons/daughter with disabilities. However, current information sources allow neither quantitative nor qualitative understanding of how ageing parent/caregivers make decisions or how they cope psychologically, physically, and financially with an ageing son/daughter with disabilities, and also how ageing persons with disabilities understand their lives and view the future.

By providing a full life-span approach, results reported here build on and extend a body of previous research in N. Ireland regarding the experiences and needs of ageing parent/caregivers of sons and daughters with disability (Dillenburg & McKerr, 2009a; 2009b; 2010) and younger parents/caregivers of children with disability (Dillenburg & Keenan et al., 2010; 2011; Keenan & Dillenburg, et al., 2007; 2010). Furthermore, the results illustrate the consequences of current ageing and childcare strategies as experienced by parent/caregivers and their sons/daughters with disabilities, thus enabling policy makers and professionals to ‘hear the data’.

Recommendations are formulated for future childcare and ageing caregiver strategies, policies, and practice.

Key findings:

Parent/caregivers of son/daughter with disabilities are in it for the ‘long-haul’ and they experience first-hand the social, physical, and emotional cost of care giving.

Ageing was an issue that worried all participants across the lifespan, although during the early years they focussed more on diagnosis and early intervention, while later in the lifespan they were more concerned with issues around employment, day-care and respite, often neglecting making actual plans for the future.

- **Parent/caregivers are twice as likely as the general population to have poor psychological health (i.e., they had high GHQ-12 scores);**
- **Parent/caregivers are less likely to be in full-time employment than the general population, thus more likely to be worried about financial provision, however, they would like to have opportunities to seek employment and training;**
- **Their family relationships with their partners, other children, and their own parents are affected by long-term care giving, i.e., there was a higher likelihood of divorce or feelings of neglect of siblings, and parent/caregivers would like to spend more quality time with other members of their family;**

With regard to their sons/daughters with disabilities,

- **Parent/caregivers are the main managers and ‘organisers’, with concerns about their sons/daughters’ life-skills related to mobility, communication, and challenging behaviour;**
- **Parent/caregivers are ambitious for their sons/daughters and were very selective regarding services, with respite/short breaks and daycares being the most important services;**
- **Parent/caregivers worry mainly about safety/security, staff sensitivity to individual needs, and flexibility when selecting services;**
- **Social workers are the main contact point for service allocation, however many parent/caregivers do not receive enough information about available support, e.g., they are not aware of statutory carer assessments and confused Disability Living Allowance (DLA), based on assessment of the person with disabilities, with Carers Allowance, based on assessment of caregivers.**
- **Parent/caregivers rely heavily on voluntary sector services and informal care arrangements; the only service that is entirely free for all service users is adult day-care in specialised centres;**
- **Parent of young children with disabilities are mainly concerned with giving their children the best start possible and worry about the severe lack of good quality early behavioural interventions. Many opt for behavioural home programmes but have to fund these privately;**

- **Due to lack of available well-trained childminders willing to take on children with disabilities (especially autism), parent/caregivers do not avail of registered childminding and home childcare services;**
- **Parent/caregivers appreciate support from professionals and from other parents of children with disabilities, requiring as much information as possible, as early as possible, and looking for long-term sustained commitment to services, rather than once-off treatments at infrequent intervals;**
- **Ageing parent/caregivers receive decreasing levels of care giving support from extended family as sons/daughters aged;**
- **With increasing age across the lifespan, parent/caregivers worry more and more about the future, yet 70% of them have not made firm future plans;**
- **Parent/caregivers generally feel they know more about their son/daughters' needs than service providers, but service providers do not always listen carefully enough.**

Parent/caregivers felt that they should be viewed as consumers/customers rather than users of services, who have a voice and high expectations for their sons/daughters and educate themselves about quality of services. They were selective and did not feel that as far as services was concerned anything was better than nothing. (Would you send your son/daughter there?). They were also ambitious for themselves and their sons/daughters, in terms of education and employment, basically wanting to lead as 'normal' and full an adult life as possible. They want the same as every parent for themselves and for their children: high hopes and expectations of a fulfilled life.

Service providers acknowledged that listening and communication were some of the most valued services. Service providers worried about cutback for services that were already stretched and acknowledged that lack of joined-up thinking between children and adult services and education, health, and social care were a problem. Service providers felt that parent/caregivers were generally satisfied if and when they received good quality services.

Young adults with disabilities expressed their appreciation of what parent/caregivers did for them and found living at home a positive experience. They were ambitious and articulate and had strong and well-founded opinions. Young adults with disabilities

wanted as much independence as possible, living lives that were as similar to other young people their age as possible, e.g., having relationships, travelling, working, taking part in sports, learning to drive a car. They enjoyed respite and short breaks and holidays, clubs and a busy social life and used modern technology extensively for entertainment and social networking.

Key recommendations

Parent/caregivers want to get the best available life for their son/daughters. They are ‘ambitious’ for their sons/daughters (Lamb, 2009). In order to achieve this, the main recommendations from this research are as follows:

- 1. Parent/caregivers should be helped to find dependable peer support throughout the lifespan, with signposting for access to support groups through the distribution of regularly updated booklets and information on webpage directories. This should be achieved through the existing framework for carers’ support within Health and Social Care Trusts, and monitored by the Carer’s Co-ordinators.**
- 2. Encourage and empower parent/caregivers to self-determination, by listening carefully to individual needs and working in true partnership and treating parent/caregivers with respect. This is in line with DHSSPS *Priorities for Action* (2), which emphasises the importance of PPI (Patient and Public Involvement) and the engagement of HSC Trusts with both carers and individuals with disabilities (2010, 19). Providers should offer a range of opportunities for service evaluation as well as a regular formal review, and take up this more diverse range of feedback within carer/client/Trust fora; the results should inform the annual DHSSPS Priorities review.**
- 3. Cost-effective, evidence-based early intensive behavioural intervention (EIBI) should be offered to all children diagnosed with ASD and other developmental disabilities and early advice regarding futures planning should be provided routinely.**
- 4. Structures are already in place for parent/carer consultation in transitions between Children and Adult’s services in all HSC Trusts, and within Education and Library Boards for transition from secondary level schooling into employment, further and higher education. Extending this service to include information on futures planning would be timely, as would the compilation of a directory of resources such as charities and carer’s organisations which can offer appropriate financial and legal advice.**

5. **View individuals with disabilities as valued family members who can and should lead a full and enjoyable life. Employers for Childcare (2011, p. 75) have identified the need for an integrated childcare strategy for children with disabilities/special needs. Recommendations from the present research go even further: there should be an integrated lifespan care and support strategy which draws in expertise from all agencies involved with disability services, parent/carers and service users.**
6. **Deliver joined-up services across education, health, and social care (and Children's and Adult services) that utilise an effective two-way process of communication and exchange of information between professionals and caregivers. DHSSPS identify a 'whole life approach' as a priority in disability services, and also acknowledge the increasing importance of multi-disciplinary and multi-agency co-operation in service provision (Priorities for Action 2010-2011, p.37, p.45). Our research fully supports this approach. In addition, in order to ensure the effectiveness of these strategies there should be measurable outcomes of services and interventions and carer/client involvement. The need for detailed individualised measures of effectiveness should be built into all strategies.**
7. **Access to clear information on benefits, direct payments, carers' assessments and work support schemes should be available to all carers. While acknowledging that this involves input from a number of agencies, carer's services within HSC Trusts should ensure that key workers compile a summary of up-to-date information on disability benefits and services that they distribute effectively to clients.**
8. **When carers reach statutory retirement age and continue to carry out caring responsibilities, they should not be penalised financially by a change in benefit status. Many ageing carers did not receive a carer's assessment and as needs change with age, it is important to keep the carer assessment up-to-date. A full carer's assessment should be mandatory at regular intervals, especially once carers reach statutory retirement age.**
9. **For pre-school children, all registered day-care establishments (crèches, nurseries, playgroups etc) should have the equivalent of the Special Educational Needs Co-ordinator (SENCO)¹ who would be responsible for ensuring staff training was adequate for special needs provision. To increase availability of childminding services, there should be compensatory payments to the provider, to cover the economic impact of looking after fewer children. Staff should receive appropriate training to enable them to deal with issues related to specific disabilities, and childcare qualifications (for example, NVQ**

¹ In schools, the SENCO is a teacher who is responsible for the operation of the special needs policy and co-ordination of services. For a full description of the role, see http://www.deni.gov.uk/the_code_of_practice.pdf, p. 6.

and BTEC) should incorporate a substantial component that relates to disability.

- 10. For school age children with disabilities, given that staff will already have an established skills base, in-school provision (such as Breakfast, After school and Saturday Clubs and Holiday Schemes) should be the major focus of any expanded childcare strategy.**
- 11. Colleges, workplaces and adult centres should put in place robust, individualised support systems that will both enhance the life-skills and the education and employment opportunities of adults with disabilities. This would transfer some of the most time consuming responsibilities from parent/carers, allowing improved participation in social and economic activities for carers and sons/daughters with disabilities.**
- 12. Both policy makers and practitioners should be knowledgeable about the most up-to-date, evidence-based, international best practice interventions to ensure that individuals with disabilities achieve their full potential across the lifespan. Professional development for staff should include regularly updated training courses on disability issues in general, on caring for children with disabilities across the life course, and on evidence-based interventions.**

SECTION 1. Introduction

In their 2011 report *Carers in the Spotlight*, Carers NI note that there are currently nearly 200,000 carers in Northern Ireland (26% of the population), carrying out unpaid work to the value of £4.4 billion. 'It is estimated that the average carer is saving the country £15,260 per year. However, carers themselves are paying a significant personal cost'. The latest figures available from the Northern Ireland Census (2001) records 184434 carers, aged from 5-7 years (n =292) to 90⁺ years (n= 120).

In England, the UK government is investing £4 billion over three years ... to support early years and childcare provision [and] the Irish government is spending €575 million on its current five-year National Childcare Investment Programme ... In Northern Ireland, there has been no comparable level of public investment in childcare. (Fawcett, 2009).

The dearth of information on the supply, demand, and quality for childcare in general, and childcare for children with disabilities in particular (Family Support, 2011) is matched by the growing concern about a rapid increase in an ageing population, especially with regard to ageing parent/caregivers of ageing sons/daughter with disabilities. In the Republic of Ireland and Northern Ireland, over 12,500 people with learning disabilities are living with family carers; 50% of them live with both parents, approx. 30% live with one parent, and just under 20% live with other relatives (Barron et al., 2006). However, current information (e.g., Ferguson & Devine, 2011; Scullion & Hillyard, 2005) allows neither quantitative nor qualitative understanding of how ageing parent/caregivers and ageing persons with disabilities understand their lives and view the future or make decisions and cope both financially, psychologically, and physically.

There are many questions: What does home life look like when you care for an adult son/daughter with disabilities? How many households are expected to need services of different types or access to respite care? Across the lifespan, what do parents think of current services and what is their view of what the future holds for their child? What restrictions are placed on them due to caring responsibilities and are they accessing all of the services and benefits they are entitled to? What are the impacts on their home life in terms of their own health, opportunity for recreation or travel? Do

these restrictions impact across the social and age gradient or are they concentrated in areas of highest deprivation and poverty?

By providing a life-span approach, this report extends a body of previous Northern Irish research regarding the experiences and needs of ageing parent/caregivers of sons and daughters with disability (Dillenburg & McKerr, 2009a; 2009b; 2010) and younger parents/caregivers of children with disability (Dillenburg & Keenan et al., 2010; McConkey et al., 2008).

Furthermore, it illustrates how governmental ageing and childcare strategies are experienced by parent/caregivers and their sons/daughters with disabilities, thus enabling policy makers and professionals to 'hear the data'. Finally, recommendations are formulated for future childcare and older people strategies, policies, and practice.

1.1 Literature review

1.1.1 Families across the lifespan

In Northern Ireland, there are approximately 464,000 children and young people under 19 years (nearly 1/3 of the population; OFMDFM, 2006) most of whom live at home with their families. At the same time, approx 1/3 of the population is aged over 50 years; 334,000 people are aged over 60 years of which 53,000 people are over 80 years of age (Older People's Advocate, 2009). Within this age distribution, the 'family' clearly no longer is defined by the nuclear structure of a married couple with 2.1 children. In their report *Families Matter* (2009), DHSSPS defines a family as consisting 'of any child or young person ... and their primary caretakers. A primary caretaker can be a parent, an expectant mother or other biological relative or any person involved in bringing up the child or young person who has parental responsibility for that young person or child' (DHSSPS, 2009, p.7). In reality, though, the 'family' includes members who are not biological relatives, e.g., stepparents or adoptive children, and the extended family, including older generations, e.g., grandparents.

Across the lifespan, growing older affects both parents and their sons/daughters, with or without disabilities. A child/young person is a person under the age of 18;

for young people leaving care and disabled young people the age is 21 (DHSSPS, 2009). Parenthood is viewed as a lifelong process as ‘issues of service provision and futures planning permeate throughout the process of bringing up a child with disabilities’ (Dillenburger & McKerr 2009a, p. 11); inevitably, this means that a number of parents will continue to provide care for their adult sons and daughters as they themselves become older (for the purpose of this report, ‘older’ is defined as the default retirement age of 65 years).

The anti-poverty and social inclusion strategy (OFMDFM, 2010) focuses on the 327,000 people, including 102,000 children and 54,000 pensioners, who live in poverty in Northern Ireland. It aims to ensure that every child (aged 0-4) should develop their full potential regardless of social background and to allow all children and young people (aged 5 – 16) to experience a happy and fulfilling childhood and education. It also seeks to ensure that all adults participate fully in economic, social and cultural life and that people beyond the working age remain valued, respected, independent, and active citizens and enjoy a good quality and safe life in the community (OFMDFM 2010, p.8).

However, ageing can be a difficult process. For example, in Northern Ireland, over 40% of people of default pension age have no other income, apart from state retirement pension or other state benefits (Marsden et al., 2002) and Walker (2003) pointed out four different levels that curtail independence and standard of life for people as they age:

- ***Insufficient income to participate fully in society;***
- ***Living in remote rural areas or disadvantaged urban housing estates;***
- ***Insufficient access to services and transport;***
- ***Experience ill health and disability progressive with age.***

These factors affect people’s confidence and feelings of being valuable member of a family, community or society more generally. For those caring for a son or daughter with disabilities, these issues are compounded by concerns around maintaining adequate care provision for their sons/daughters as they grow older. In Northern Ireland the prevalence of disability in individuals aged between 60 and 74 years is 41%, rising to 60% in those over 75 years (NISALD 2009, p.19). At a point in life

when they might expect to be ‘cared-for’ themselves, many parents will still be undertaking considerable responsibilities on behalf of their children.

1.1.2 Disability and care giving

When talking about sons/daughters with disabilities across the lifespan it is difficult to find the right terminology. We cannot simply talk about children or young people, although for parents they will always be ‘their children’. For the sake of this report, we opted for the term ‘sons/daughters’, however, we expect that conclusions also apply to those who are caregivers across the lifespan for other relatives, such as nieces or nephews, grandchildren, or cousins.

It is important to remember that there is a difference between disability and impairment. ‘An impairment is a specific difficulty that a person might have and might be considered to be a physical, psychological or other kind of impairment. Disability is a restriction in independence or well being that is brought upon people with impairments’ (Messick & Clark, 2005, p.72). Ultimately, whether or not someone experiences a disability depends on the complex interaction between health conditions and environmental and personal factors surrounding one’s life. According to UNICEF (2011) ‘disability serves as an umbrella term for impairment, activity limitations or participation restrictions’. Under the Disability Discrimination Act (DDA; 1995), disability is defined as a physical or mental impairment that has a substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities (Marsden et al., 2002). In the UN Convention on the Rights of Persons with Disabilities (2006), disability is defined as including persons ‘who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’ (p.1).

While *Understanding the Needs of Children in Northern Ireland* (DHSSPS, 2008) promised to ‘introduce a standardized approach to carrying out an assessment of a child's and their family’s additional needs and deciding how those needs should be met’ (p.29), there still is no systematic registration of individuals with a disability and therefore much of the information presently in the public domain has to be gathered using survey data from general population studies. For example, Northern Ireland

Survey of *Activity Limitation and Disability* (2007) indicated that 18% of individuals living in private households have a disability in Northern Ireland, and almost two out of five households (37%) include at least one person with a disability. An estimated 6% of individuals with disabilities are children (CDSA, 2010). There is a higher prevalence of disability among boys (8% of all boys under 15 years of age) than girls (4% of all girls under 15 years of age), and both intellectual disabilities and social and behavioural problems were more prevalent in boys (NISALD, 2007).

Over 80% of individuals with disabilities are cared for in their own homes across their entire life course, by their parent/caregivers as they themselves grow older (NHS Ealing, 2011). Poverty is one of the major issues for these families. In Northern Ireland, 52% of work-less households include a disabled adult, compared to only 17% of work-rich households (Marsden et al., 2002). Defining consensual poverty as the lack of at least three deprivation items combined with low income, defined by the Department of Work and pensions as below 60% of median income, Hillyard et al. (2003) found that 100% of households that were work-less lived in poverty. The same is true for 56% of households with one or more members with a disability, 36% who were caring for an adult, 32% who caring for children, and 67% lone parents. Despite the fact that the recent *Lifetime Opportunities Anti-Poverty and Social Inclusion Strategy* (OFMDFM, 2010) aims to tackle these problems, solutions are still some way off, and ‘the focus of future policy and effort must be on the 327,000 people here, including 102,000 children and 54,000 pensioners, who remain in poverty’ (p. 2).

In the UK, there are nearly 6 million unpaid caregivers, of whom 184,429 live in Northern Ireland. Unpaid family caregivers provide 96% of all care needs of ill, frail, or disabled family members, friends, or partners and the numbers of people caring for more than 50 hours per week is currently estimated as 46,538 (Carers NI, 2011; Redmond, 2010). The latest Northern Ireland Census figures available (2001) correspond closely, giving the total number of unpaid carers as 184,434 of whom over a quarter (46,543) provide more that 50 hours of care a week, including 64 people aged over 90 years of age (NISRA 2005). At the same time, 70,369 of caregivers are adults in full-time employment with a further 26,514 in part-time employment. This indicates that a considerable number of caregivers balance work and family

commitments. Caregivers save the Northern Ireland economy an estimated £4.4 billion each year (Carers NI, 2011).

While most caregivers are adults, some are children ‘under the age of 18 whose life is affected by providing significant care, assistance, or support to a sick, or disabled relative at home’ (British Medical Association, 2010, p.4). It is estimated that there are currently 8,352 young carers in Northern Ireland, of whom 712 provide care for over 50 hours each week, and it is likely that many will receive no formal support from statutory or voluntary agencies (BMA, 2010). They themselves can be regarded as ‘a child in need’ as defined by The Children (Northern Ireland) Order 1995, as their ‘health or development is likely to be significantly impaired, or further impaired’ or they are ‘unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision of services by an authority’ (BMA, 2010, p.4).

1.1.3 Care within the family

The needs of families who parent a son/daughter with disability in the early years are mainly concerned with diagnosis (Keenan et al., 2010), appropriate and effective early interventions and education (Dillenburg et al., 2011), and planning for the immediate future (Keenan et al., 2007). Ageing parents who have cared for their sons/daughters with disabilities all their lives are particularly concerned with social exclusion, poverty, lack of life skills, and worry about what will happen to their loved one in the futures, once they are no longer able to care (Dillenburg & McKerr, 2009a, 2009b; 2010). It is particularly worrying that lack of life and self-care skills in persons with disabilities has been associated with increased mortality rates (Warren & Knight, 1982).

Financial hardship and increased workload due to atypical childcare (e.g., more direct supervision, more washing, more sleepless nights) affect women more than men, especially where fathers are not fully involved in childcare (Cuskelly et al, 1998; Ricci & Hodapp, 2003). Crowe and Florez (2006) found that when compared with mothers of typically developing children, mothers of children with disabilities spent significantly more time in childcare activities and significantly less time in

recreational activities. As children got older, the gap increased. Dabrowska and Pisula (2010) compared stress levels and found that mothers of children with Autism Spectrum Disorder (ASD) experienced more stress than mothers of children with Down Syndrome or mothers of typically developing children. They also experienced more stress than the fathers of their children. Obviously the inability to remain in gainful employment due to increased childcare duties as well as the increased cost of caring for a child with disabilities and high divorce rates (up to 80%) adds to stress and exclusion (Parish et al., 2005). Seltzer et al. (2001) confirmed that social participation in general was adversely affected by caring for a child with disabilities.

Ultimately though, ‘parents of children with special needs are uniquely qualified to help each other. The challenge is to ensure that health professionals are aware of the potential benefits of parent-to-parent support’ (Kerr & McIntosh, 2000, p.309). The main challenge is for professionals to recognise when parents are more knowledgeable than professionals and to ensure that service providers listen to parents and work in true partnership with families (Dillenburger et al., 2010).

1.1.4 Care outside the family

While in the past services were focussed on one specific ‘client’ group, increasingly services for families caring for a child with a disability are supposed to focus not only on the child’s needs but on the whole family (Truesdale-Kennedy et al., 2006). Ideally assessment should take place within the context in which the family live. However this can cause problems and stress. It can be difficult to arrange for meetings that all family members can attend, involving people other than service providers and peers outside the family, and come to a consensus (Robertson et al, 2007). Consequently, social services are not always delivered adequately, timely, or in partnership (NHS Ealing, 2011).

In Northern Ireland, many parents are able to utilise some kind of childcare outside the family (Employers for Childcare 2010). Although day care settings and childminders account for the majority of provision for working parents, they also rely on a mix of formal and informal care, the latter usually provided by other family members such as grandparents or siblings. During the early years formal care includes

pre-school, playgroup, or private day-care; when the children reach school age, it includes after-schools or breakfast clubs, activity and youth groups.

For parent/caregivers of sons/daughter with disabilities the organisation and availability of childcare outside the home is not as easy (DHSSPS, 2003; Dixon et al., 2004; Godfrey, 2003; Gray & Breugel, 2003; McTernan & Godfrey, 2006). Winter and Connolly (2005) identified seven domains that affect generally availability and quality of childcare (in brackets their weighting with regard to the Noble Index of Multiple Deprivation): income (25%), employment (25%) health and disability (15%), education, skills & training (15%), geographical access to services (10%), social environment (5%), and housing stress (5%). The out-of-home care of a child with disabilities can be impacted negatively by all of these. In addition, Buell et al. (1999, p.217) identified three 'primary barriers' for those who provide out of home childcare for children with disabilities: lack of knowledge about disabilities, limitations that would be imposed in caring for other children, and the need to provide or purchase specialist equipment.

For young adults there are day centres and sheltered employment, training or Higher and Further Education (HFE) courses, and social groups. Parents of sons/daughter with disabilities also use short-term residential care, such as respite care ('short breaks') or medium and longer-term residential placements (including hospices) and family support schemes, such as holidays organised by voluntary agencies.

1.2. Policy and legal context

Childcare inside the home (inter-family) as well as outside the home (extra-family) occurs within a policy and legal context that promotes care of sons/daughters with disability within a family context.

Children with disabilities are best cared for and nurtured within their own family environments provided that the family is adequately supported in all aspects... In this context, support should be extended to children who are affected by the disabilities of their caregivers. (UNCRC, 2007, p.11)

McTernan and Godfrey (2007) highlight important legislative shifts in services for children, away from a 'service orientation (how do we get the child to the services) in

favour of a needs orientation (how do we design the services around the child)' (p. 220). However, these are not always implemented and the recent Manifesto of *Children with Disabilities Strategic Alliance* (CDSA, 2010) calls for improvements across seven key areas, including public services, family support, short breaks, suitable childcare and educational provision, and leisure and cultural activities. Of course, there are a plethora of governmental policies, strategies, and guidelines that could be referenced in the context of this research. We outline very briefly here just some of the key policies that apply directly to the research reported here.

Historically, *Every Child Matters* (2003) was an important step in defining the delivery of services for children, including those with disabilities. It outlined a framework of services to support all children, particularly those with specific needs and children at risk, in care, in poverty, or having been abused. It emphasise the importance of accountability and joined-up thinking between Government agencies. The *Children's National Services Framework* (NSF; 2004) had similar aims for services for children, young people and pregnant women, in effect for individuals from conception to adulthood. In his foreword John Reid, then Secretary of State for Health, wrote 'Services are child-centred and look at the whole child - not just the illness or the problem, but rather the best way to pick up any problems early, take preventative action and ensure children have the best possible chance to realise their full potential' (NSF, 2004)

In Northern Ireland, key legislation such as *The Children (Northern Ireland) Order* (1995), of course, applies to all children, including those with disabilities, but the *Equality Act (2010)* for England and Wales provides even better protection of disabled people as they grow older and prevents disability discrimination in many areas, including employment, education, and access to goods, services and facilities. The Act also protects people who do not have impairments themselves but who are associated with a disabled person, such as carers or parent of a disabled person. In Northern Ireland, the Equality Commission (2011) has called for these advances to be applied fully in local law.

The three main local strategy documents that set the context for this research are

- The strategy for children: *Our Children and Young People – Our Pledge* (OFMDFM, 2006);
- The strategy for ageing: *Ageing in an inclusive society: Promoting the social inclusion of older people* (OFMDFM, 2007); and
- The anti-poverty and social inclusion strategy *Lifetime Opportunities* (OFMDFM, 2010).

The governmental children's strategy (OFMDFM, 2006) set out the shared vision that all children and young people (including those with disabilities) should be healthy; enjoying, learning and achieving; live in safety and with stability; experience economic and environmental well-being; contribute positively to community and society; and live in a society which respects their rights.

The child strategy promised 'the development of a policy for children with a learning disability, which will take account of the recommendations of the review into Learning Disability in Northern Ireland and the Equal Lives report. It was intended that this would be the blue print for the reform and modernisation of services for children with a learning disability' (OFMDFM, 2006, p. 60). However, the second three-year action plan (covering 2008-2011; OFMDFM, 2008) that was aimed to implement the children's strategy is overshadowed by an economic climate of substantial general cutbacks and imposed savings. 'In the period 2010-11, £3.6 billion will be spent on health and social care ... but efficiency savings of some £204 million will also be needed' (Health and Social Care Board and the Public Health Authority, 2010).

The strategy for ageing (OFMDFM, 2007) aims to ensure that 'age related policies and practices create an enabling environment, which offers everyone the opportunity to make informed choices so that they may pursue healthy, active and positive ageing' (p.13). Six strategic objectives were formulated to turn this vision into reality: to ensure that older people have access to financial and economic resources to lift them out of exclusion and isolation; to deliver integrated services that improve the health and quality of life of older people; to ensure that older people have a decent and secure life in their home and community; to ensure that older people have access to services and facilities that meet their needs and priorities; to promote equality of opportunity for older people and their full participation in civic life, and challenge ageism wherever it is found; and to ensure that Government works in a coordinated

way interdepartmentally and with social partners to deliver effective services for older people (p.14-15).

The anti-poverty and social inclusion strategy (OFMDFM, 2010) focuses on the 327,000 people, including 102,000 children and 54,000 pensioners, who live in poverty in Northern Ireland. It aims to ensure that every child (aged 0-4) should develop their full potential regardless of social background; to allow all children and young people (aged 5 – 16) to experience a happy and fulfilling childhood and education; to ensure that all adults participate fully in economic, social and cultural life; and to ensure that people beyond the working age remain valued, respected, independent, and active citizens and enjoy a good quality and safe life in the community (p.8).

The research question addressed here relates to these strategies and asks: ***What are the main childcare issues for sons/daughters with a disability across the lifespan, as they and their main caregivers grow older?***

1.3 Ethical approval

The School of Education (QUB) Research Ethics Committee granted ethical approval for this research. The research was conducted under Queen's University of Belfast Research Governance. In order to give assurance of confidentiality and protect vulnerable participants, all participants read and retained the Participant Information sheet and a copy of the signed Consent Form (Appendix 1).

Section 2: Methodology

2.1 Participants

In total 51 participants took part in this research either by direct interview or as part of a focus group; this included 38 service users, i.e., 29 parent/caregivers and 9 young adults with learning disabilities; as well as 13 service providers from the statutory and voluntary sector, e.g., child-minding association, social services, carers' organisations. Table 1 shows a summary of participants and method of data collection.

Table 1: Research participant summary

Stakeholder group	Method of data collection	Number
Service users:		
Parent/Caregivers	Individual interview	20
Parent/Caregivers	Focus group	9
Young adults	Focus group	9
Service Providers	Individual interview	13
Total participants		51

2.1.1 Parent/Caregivers- individual interviews

Family caregivers are notoriously difficult to recruit for research purposes, mainly because they care within the context of family and there is no register or easy access tool available. In order to circumvent general problems with accessing 'hidden and hard to reach' populations (Patel, Doku and Tennakoon, 2001; Teitler, Reichman, & Sprachman, 2003), a gatekeeper approach was used for most of the participant recruitment using convenience sampling (Robson 2005). This meant that a brief summary of the research was sent to the headquarters of service provider organisations within the voluntary sector for distribution to all families caring for children with disabilities on their databases. These groups were identified using Duffy's (2008) and Dillenburg and McKerr's (2009) lists of contacts. These lists were expanded through snowball sampling/respondent-driven sampling (Salganik & Heckathorn, 2004). The groups reflected service providers for a full range of physical, developmental, cognitive, communication, and sensory disabilities.

Those parent/ caregivers who agreed to participate contacted the researchers directly, by telephone or e-mail, and received further details of the research. A follow-up

telephone call was made to confirm participation and to arrange a suitable time and place for interview, usually in the family home. In all, twenty-three carers came forward, including two married couples (Carers 11 and 12; Carers 19 and 20) who participated in a joint interview. Three parent/caregivers who had expressed an initial interest withdrew, one due to her child's illness, and the other two did not follow up interview date requests; no one who came forward was rejected. Table 2 displays background information for each parent/caregiver participant in individual interviews. The age range of these participants was 32-78 years (average 49.6 years, n=19; one participant, Carer 8, preferred not to give her exact age). The age range of their sons/daughters was 3-53 years (average 18.6 years, n=19). The relatively high proportion of son/daughters with autism (63%) reflected the much higher prevalence of this condition (1:100) *vis a vis* other childhood disabilities (Keenan et al., 2007; McConkey 2010). Of the 12 individuals with autism 59% (n=7) had dual diagnoses with a co-existing conditions such as epilepsy or learning difficulties (LDs).

Table 2: Parent/Caregiver – Details of individual interviewees

Carer	Gender	Age	Location	Details of son/daughter
1	Female	39	Rural	Son (aged 10) autism & LD ¹
2	Male ⁴	41	Urban	Son (aged 5) autism
3	Female	54	Urban	Son (aged 29) Asperger's syndrome
4	Female	42	Village	Son (aged 13) autism & LD ¹
5	Male	53	Urban	Son (aged 21) autism, LD ¹ & epilepsy.
6	Female	45	Urban	Daughter (aged 11) autism
7	Female	41	Urban	Son (aged 12) autism & epilepsy.
8	Female	60+	Urban	Son (aged 38) cerebral palsy
9	Female	43	Urban	Daughter (aged 13) complex needs
10	Female	60	Urban	Son (aged 27) LD ¹
11	Male	78	Urban	Son (aged 53) Down's Syndrome
12	Female ⁴	77	Urban	
13	Female	50	Urban	Son (aged 21) Down's syndrome
14	Female	32	Urban	Daughter (aged 5) Asperger's syndrome Son (aged 3) Global Dev.Delay ²
15	Female	56	Village	Son (aged 17) autism
16	Female	50	Urban	Daughter (aged 12) autism & severe LD ¹
17	Female	49	Urban	Son (aged 17) autism & LD ¹
18	Female	64	Rural	Daughter (aged 39) severe LD ¹ , ChBeh ³
19	Female	34	Urban	Daughter (aged 6 ½) autism, severe LD ¹
20	Male	34	Urban	

¹ LD=Learning Disabilities;

³ ChBeh= Challenging Behaviours

² Global Dev.Delay = Global Development Delay

⁴ Did not describe themselves as main carer

2.1.2 Parent/care givers- focus group

In addition, nine parent/caregivers who cared for a total of 11 children took part in a focus group. They belonged to a support group for parents of young children who received an early intervention support programme. Eight of the women cared for their own child, while one cared for her nine-year-old granddaughter. She attended the group to support her daughter, whose son was recently diagnosed with autism. As part of the support programme, the children (with the exception of the nine-year-old) all attended an early intervention programme in the nursery adjoining the focus group room. With the exception of the nine-year-old, the children were all boys aged 2 years 5 months to 6 years. Table 3 gives details of the parent/caregiver participants in this focus group and their children. Unless otherwise specified the children had a diagnosis of ASD. All participants came from the same Health and Social Care Trust area.

Table 3: Parent/caregivers - Details of participants in Focus Group

Carer	Caring status	Employment	Target child	Age at Diagnosis
Female	Main carer	None	Boy (aged 4)	2 years
Female	Main carer	None	Boy (aged 6) Boy (aged 3)	3 years 4 mths, 2 years 4 mths
Female	Main carer	Full-time	Boy (aged 4)	2 ½ years
Female	Main carer	None	Boy (aged 2)	2 years
Female	Main carer	None	Boy (aged 4 ½) Boy (aged 3 ½)	<3 years <3 years
Female	Main carer	Part-time	Boy (aged 3)	2 years
Female	Shared care	Part-time	Boy (aged 3)	3 years
Female	Main carer	None	Girl (aged 9)	6 months Dev.Delay
Female	Main carer	None	Boy (aged 4)	3 yrs

2.1.3 Service users-focus group

Nine participants (four women and five men) took part in the service user focus group. They belonged to a self-advocacy group for young people with learning disabilities that was facilitated by a voluntary sector organisation. They were aged between 19 and 29 years (average age = 23.5 years). Group members are drawn from across Northern Ireland. Table 4 details the age and place of residence of participants.

Table 4: Service users- Participant details in Focus Group

Gender	Age	Place of residence	Accommodation shared with
Female	26	At home	Parents
Female	28	At home	Mother + brother
Female	22	At home	Mother + grandmother
Female	24	At home (on housing waiting list)	Parents + 2 brothers
Male	29	At home	Parents
Male	19	At home	Parents + brother
Male	22	At home	Parents
Male	20	At home	Parents + 2 brothers + sister
Male	22	At home	Parents

2.1.4 Service Providers - individual interviews

The Regulation and Quality Improvement Authority (RQIA), the independent regulatory body who registers some aspects of childcare services, was contacted to obtain service provider details, but although they provided details of registered residential homes offering respite/short breaks for children with different disabilities and also information regarding Trust management, a full list of registered childcare services was not available.

Social workers in ‘disability teams’ in all five Health and Social Care Trusts were contacted, and disability support groups were located as outlined earlier. During the initial contact by telephone, the aims of the research project were outlined, and the person within the organisation best placed to participate was identified. Those who considered taking part received further written information (Appendix 1). A follow-up telephone conversation confirmed the decision to take part or otherwise and interviews were arranged, usually within the workplace.

In all, 13 service provider (four statutory and nine voluntary providers) participants took part, which represented a full spectrum of services, including residential care, respite or short breaks, social/advocacy groups for young adults, home intervention programmes, childminding services, day care (adult and children), after-schools and summer schemes. Table 5 displays the background for each service provider participant.

Table 5: Service providers – Participant details for individual interviewees

Provider	Age of service users	Disability
Statutory 1	3-18 years	a-e
Statutory 2	0-18 years	a
Statutory 3	18 ⁺ years	a-e
Statutory 4	0-18 years	a-e
Voluntary 1	10-90 ⁺ years	a-e
Voluntary 2	2-33 ⁺ years	a,c,d
Voluntary 3	7-18 years	a-e
Voluntary 4	6 months- 12 yrs	a-d
Voluntary 5	8-18 years	a-e
Voluntary 6	0-65 years	b+a,d,c,e
Voluntary 7	18 ⁺ years	e
Voluntary 8	0-18 years	d+(a, b,c,e)
Voluntary 9	8-18 years	a

- a. Learning disabilities
- b. physical disabilities
- c. behavioural issues
- d. sensory impairments
- e. mental health issues
- f. other disability

2.2 Research tools

Semi-structured, responsive interviews (Rubin & Rubin 2005) were developed specifically for this project for (1) parent/caregivers and (2) service providers. Where possible, appropriate interview questions were aligned with similar questions from other tools, such as those developed by *Employers for Childcare* (Dennison & Smith, 2010) to allow for direct comparisons. Focus group questions were aligned with relevant interview topics. The interview schedules were reviewed by the Project Steering Committee and a pilot study was conducted with a small number (n=3) of volunteer parent/caregivers (Appendix 2).

2.2.1. Parent/Caregiver interview

For parent/caregivers, interview questions related to demographic background, family composition, details about the son/daughter with disabilities, support received from service providers, financial aspects, social activities and opportunities for son/daughter, social validity of services, and prospective needs (Appendix 2). In addition, caregivers who participated in individual interviews completed the General Health Questionnaire (GHQ-12; Goldberg et al., 1996), a standardised measure of psychological wellbeing used widely in Northern Ireland (ARK, 2011). The GHQ-12

also is widely used, nationally and internationally. It is not a diagnostic tool, although it has been used as an indicator of mental health and stress (Lesage et al., 2011). The GHQ has high levels of reliability ($\alpha > 0.88$; Hankins, 2007) and highly significant validity (Tait et al., 2002). Cross-cultural evaluations for example, have shown significant negative convergence with global quality of life scores ($r = -0.56$, $P < 0.0001$; Montazeri, 2003) and sensitivity and specificity scores of 80.6% and 79.3% respectively (Lee et al., 2005).

2.2.2 Parent/caregiver and service user focus groups

The focus group format was chosen and the questions were selected so as to elicit responses on general themes identified from the research question (Appendix 2). The questions regarding participant profiles reflected the different perspectives of the two groups, i.e., service users (i.e., sons/daughters) and parent/caregivers. The parent/caregiver focus group members were asked about their child's age (not their own age as this seemed inappropriate in a group setting of people who did not know each other well) and questions focused on the issues around caring for a young child soon after a diagnosis of disability, such as nursery and day care provision, early intervention, and support services inside and outside the home. The young people's service users' focus group was a self-advocacy forum engaged in regular meetings and social activities over a number of years and therefore knew each other very well. The questions focused on themes such as activities and independence.

2.2.3. Service provider interview

For service providers the interview contained questions regarding the referral system, the number and range of services provided, up-take of services, training provided to staff, social validity of services, effectiveness measures, and prospective need (Appendix 2).

2.3 Research procedure

Data collection was conducted in four phases: Literature review; Pilot study; Individual interviews; and Focus groups.

2.3.1 Literature review

A review of the literature, including academic journals, reports, manuals, and service lists was conducted with regard to childcare issues for children with disabilities, especially with regard to parent/caregivers as they grow older. This involved the use of various national and international literature search engines with a range of relevant key terms.

This review also included relevant data held in various data banks, including the Northern Ireland Statistics and Research Agency (NISRA) disability survey (NISALD, 2007) and related surveys such as those available through ARK (2011), including the Kids Life and Times survey (KLT), the NI Life and Times survey (NILT), and the Young Life and Times survey (YLT).

2.3.2 Pilot study

Interview schedules were drafted and agreed by the project steering committee. Pilot studies were conducted for the parent/caregiver interview schedule and the service user interview schedule with three parent/caregivers and one service provider respectively. Feedback confirmed the validity of the schedules and no major changes were necessary.

2.3.3 Individual interviews

Individual interviews were conducted with parent/caregivers and service providers. The majority of the interviews (90%; n=28) were recorded on a hand-held device with the permission of the participants. In one instance, the recording device failed to operate and in two cases the interviews were completed by email (see below). In the latter case, the participants typed their responses to the interview questions directly into the document and returned them to the researchers. Parent/caregiver interviews lasted approximately an hour, although a small number of interviews took longer (up to 2 hours). All interviews were conducted either in the offices of a support group or parent/caregiver's own home, whichever was preferred by the interviewee.

Service provider interviews took approximately half an hour and were conducted mainly in the provider offices. Two voluntary service providers (Voluntary 7 and

Voluntary 9) were not available for personal interview due to workload pressures and preferred to reply by email as detailed above.

All tape-recorded interview data were transcribed into a word.doc document.

2.3.4 Focus groups

Focus group interviews were conducted with service users and parent/caregivers in order to obtain further focussed information in a different format and in order to allow for triangulation (Bloor et al., 2001) and transferability to be established as an indicator of data validity (Kreuger, 1998). Both focus groups lasted just over one hour and took place in a quiet group setting: Focus Group 1 with young service users took place in a specially hired hotel seminar room and Focus Group 2 with parent/carers took place in the organisation's meeting room. Both groups were familiar with the rooms, and both focus groups were tape-recorded. Notes were taken by one of the researchers while the other researcher conducted the focus group. The agency group facilitator attended the young person's focus group and facilitated communication for some of the group members. Following an 'ice breaker', the focus groups were carried out as an open discussion with minor input from the facilitator.

2.4 Data analysis

Data analysis took three forms. First, quantitative measures were collated, relating to demographic profiles of participants (i.e., gender, age, geographical location, employment etc.) and service provision (i.e., type of service, duration of service, age range and disability of the service users, geographical catchment area etc.). The summary of this information is presented in tabular format (see Tables 2-5).

In addition, those carers who participated in individual interviews completed the GHQ-12 that allowed for direct comparison with existing data sets. For the analysis of the GHQ-12, the common dichotomous scoring method was used because it allows for comparison of mean scores and frequency with other data sets. A score of ≥ 4 was considered the threshold for participants in need of full psychological assessment. The alternative, the four-point Likert-type coding, is commonly used for discrimination between individuals and was therefore not deemed appropriate. Both scoring methods have been found to be reliable ($\alpha > 0.88$) (Hankins, 2007).

Second, for qualitative analysis a ‘template analysis’ (Crabtree & Miller, 1999) was carried out, i.e., common patterns, themes, relationships were identified and differences and similarities between sub-groups were drawn out (Robson, 2005). Themes or codes were determined from reading of the transcripts and served as a template or repository for extracts from the text that provided evidence for the categories under discussion. In line with template analysis methodology, this was a relatively fluid method, allowing for changes in templates throughout the process of the analysis (Robson, 2005).

Finally, reporting of focus group findings differed somewhat from those of the individual interviews. Attention focussed more on themes for which participants showed particular emotion, enthusiasm, passion, or intensity (Kreuger & Casey 2009).

Section 3. Parent/caregiver individual interview results

3.1 Home and Family Life

In total 20 parent/caregivers took part in individual interviews, representing 18 households (2 couples and 16 individuals). Fifteen of the interviewees were married, while 4 were divorced, and one had never been married. The majority lived in two-parent families; 16 of them lived with their partner, while 4 headed single parent families. The participants' mean age was 49.6 years (range: 32-78 years of age); their partner's mean age was 42 years (range 34-77 years of age). They came from four of the five Health and Social Care Trusts (HSCT); 40% (n=8) from the Northern HSCT, 20% (n=4) from the Belfast, Southern and South Eastern HSCT respectively. No interviewees came from the Western HSCT, despite the same recruitment efforts as for the other HSC Trusts.

The participants cared for a total of 19 offspring (13 sons and 6 daughters) with a mean age of 18.6 years (range 3-53 years of age) and diagnosed with a range of disabilities (see Table 1). A total of 8 other children resided with these families (range of additional offspring 1-2). The average household size was 3.77. Of the 20 participants, all but one single parent (Carer 7) shared the care, although the mother was generally considered the main caregiver. Even when parent/ caregivers had severe health problems, (for example, Carer 12 had limited vision and other health problems) they were still involved in caring.

This doesn't affect her helping as she instructs me on how to do it. We help each other, we work as a team. (Carer 11)

While in some cases ex-husbands remained involved, e.g., Carer 3's husband provided support to find work placements for their 29-year-old son, for others this was not the case.

Once we'd split up, it was none of his business as far as I was concerned. (Carer 10)

I suppose you would say I am the main one for 5 nights a week then she goes away for 2 nights a week, so I'm still the main carer. (Carer 18)

3.1.1 Housing circumstances

Of the 18 families who participated in individual interviews, the great majority lived in an urban setting (77.8%, n=14). Many of the families had chosen their present residential location because it offered improved internal or external space (38.9%, n=7)

[Name] had more space upstairs. This whole house is bigger. The reason was based on the children's needs, above all. [Name of child] is going to stay at home, not moving out. (Carer 8)

We were very lucky to be able to close the garden off; it gave us something else to help us cope with her, as we were able to just walk down the lane. You know if she ran across the road she would have gone into somebody's house and everyone was quite understanding and there weren't the cars. That's why the doors are always locked and the keys are always in pockets, but I think only twice did she bolt and then after that she started to go sideways rather than across the road, so I think really with hindsight it's one of the best things we did because there is so much space for her. (Carer 16)

In some cases, a house was chosen because it was more suitable for a family member with very challenging behaviours.

I chose it because I don't have any neighbours, because [name] can scream so much! The isolation, really, it's a lovely place, I really like it. I had to move out of the place that was provided for me by the Housing Executive, because of neighbours, with [name]. (Carer 18)

At times, this challenging behaviour attracted negative attention from neighbours, i.e., abuse or intimidation.

And young children round about were very, very naughty. We had to move out; throwing eggs, and pulling their clothes down, boys were pulling their clothes down at the window, and oh, all sorts of things went on. Well, what can you do? I mean it was horrendous at the time but I found this place so it's like heaven here and she can scream all she wants and it doesn't bother anybody only me, so that's fine. (Carer 18)

Fewer families had chosen their present location because of proximity to their own workplace (n=3), housing costs (n=2) or proximity to schools (n=1). For almost a quarter of the 18 families, (22.2%, n=4) proximity to other family members was important, however this was not necessarily related to having a son/daughter with disabilities. In some cases it related to caring across generations.

I got married and my husband originated from this area so we decided to move back. One of the deciding factors was that my husband's parents were young and as children would come along they would hopefully step into the role for babysitting etc. (Carer 15)

I was born and raised here, I didn't want to move. I looked after my parents. They were elderly, and I was looking after them as well, up until two years ago. (Carer 4)

3.2 Emotional and physical health issues

Participants reported emotional issues and also concerns about general health, both for themselves and for their sons or daughters with disabilities.

3.2.1 Emotional issues within the immediate family

All participants considered that having a child with disabilities affected family relationships in some way, e.g., the relationship with their own parents, in-laws, siblings, partner, and other children. However, while the impact was profound, it was not always negative.

It does put a strain on family relationships because the care that's required for such a child is a lot more time consuming, a lot more physical, and just all encompassing. (Carer 1)

In a positive way, as we are more understanding of other people's problems, obviously as we are in carers' group and we are more understanding. When we just got married, I wouldn't have known what a Down's Syndrome child was. We didn't know until he was born and we were told in a very derogatory term, which was used in those days, people are more enlightened now. (Carer 11)

Almost a quarter of the families (22.2%, n=4) felt that having a son/daughter with disabilities had improved their relationships with their partners:

Probably to the betterment, it's affected it positively. As partners we have become stronger. I know that isn't always the case, but ours became stronger, because as a team we worked together very well. (Carer 13)

For some, it was not so clear-cut:

Certainly the relationship between my husband and myself is totally affected, in a good way to some extent because we're very much a tight unit and it's 'we three', but in another way it's a big strain. Just this year when he is 10 and now 11 we've managed to get a night away and that's been the first time

in 10 years. So you know it's been a big year for us, but in another way it just shows you sort of, how it does affect your family relationships. (Carer 1)

Whenever you get a diagnosis for your child like that certainly I know I had come to terms with it in my own head but my husband hadn't and so that was a big thing, and emotionally he was very upset and kind of grieving whereas I had already passed this stage and felt that possibly although I was there to support him he was not there to support me because he didn't believe [name] had autism. We are ok now. (Carer 17)

When the children were young, the effects of having a child with a disability were marked for the majority of families (78%, n=14). Three carers mentioned that the practical consequences of their children's disabilities, the day-to-day issues of organisation and coping, rather than the impact of diagnosis, had made time for relationships with partners difficult.

We don't go anywhere [laughs], the only place we go would be maybe to the shopping centre, perhaps in the summer time to the zoo, or we'd take the kids. Him and I, we don't do anything together, because we don't have anyone to look after the kids, you know for us to do anything together. (Carer 19)

I think really that is it, it's just the 'us' time that we miss, yes, we have 'me' time, as my husband would say 'you take [names] away', because he would do that sort of summer holiday bit, but it's separate families. I think it's just not having the life we thought we were going to have, you know we haven't had foreign holidays with the children, we have yet to have a weekend away or an overnight away on our own since any of the kids were born. (Carer 16)

For four carers these difficulties ended in divorce, due to the additional stress of bringing up a child with disabilities.

It's what you call the 'opportunity cost' of caring. (Carer 3)

I would say yes, he found it extremely difficult to realise that he had a daughter with such disabilities. It affected his manhood I think. (Carer 18)

Some parents spoke of having to be aware of the imbalances in attention that having a child with disabilities could produce in family dynamics.

The other thing would be as far as my other child goes. You are inclined to focus on the one child because you think they are the one that needs you the most and in fact it's very easy to miss the fact that your other child needs you just as much. Parents don't do it intentionally but it sometimes takes the other child to ask why is it always one child, why does he always take precedent. You are inclined to explain it by saying 'He has got Asperger's and I need to be there' and they need you too. It's an extra level of guilt. (Carer 15)

A number of parents spoke about a more positive effect on others in the family who had increased awareness and were able to take on responsibility. This was viewed as important in terms of a balanced and happy childhood as well as for later life, when e.g., siblings had built strong support systems and were able to contribute to planning a future for their brother or sister without parents as main carers.

My son is really protective with her and wouldn't let anybody talk her down. It's also made my brothers and sisters aware of children with disabilities.
(Carer 9)

In a way it did affect the other kids, because they had to sort of grow up. You were giving [name] more attention than them, if you know what I mean, you couldn't divide your attention as equally as you would have liked to have done and then it meant they had to grow up a bit with the helping of [name], particularly when you're on your own. (Carer 10)

There were other emotional costs, e.g., none of the four divorced parents had re-married:

I never even thought about looking for anybody else. You know, because who's going to take you when you've got 5 weans, and one with special needs? I just took that off the boiler altogether, that was a no-go area, you know? Sometimes I think, what would be the kind of life I'd have had if I had been the one that walked away and left him to it. (Carer 10)

Some of the parent/caregivers spoke about the physical and emotional costs of care giving for themselves.

The tiredness, you do get stressed, you get stressed with meeting new professionals, you get stressed with just day to day life and just looking after our son. It is tiring because it is a 24-hour job, and if his sleep pattern is bad you can go for days with not sleeping very well. (Carer 13)

It definitely has affected me emotionally, just very hard to take in all the things that are happening to your children and the fact that you really do have to keep pushing for services for them and you feel... I suppose I feel very much alone. Nobody really cares that you do have to get on with it yourself. (Carer 14)

As children got older, the personal and emotional impact lessened and parent/caregivers adjusted their perspectives.

Not so much now, but I would have got down when she was younger, I got more upset about things, like the wee ones out playing in the street. You knew

that it was never going to be [name]. That took a few years to accept, but I think it's going to get me down more when [name] is older. (Carer 6)

3.2.2 Personal health problems

The majority of participants (60%; n=12) reported experiencing a range of personal health conditions, including arthritis, loss of vision, circulatory problems, epilepsy and mental health issues; two carers reported that they were currently receiving treatment for depression.

The General Health Questionnaire (GHQ-12) mean score for participants in this study was 2.95 (range 1-12), with 35% of the participants scoring ≥ 4 . This was considerably higher than the 17% of the general population who scored ≥ 4 (ARK, 2011). However, it compared favourably to GHQ-12 mean scores of 4.35 for younger parent/caregivers (mean age 40 years) of children diagnosed with Autism Spectrum Disorders, where 48% of the participants scored ≥ 4 . (Dillenburg et al., 2010). It also compared somewhat favourably with the GHQ-12 mean score of 3.61 for older parent/caregivers (mean aged 65 years) of sons/daughters with disabilities, although 35% of the participants also scored >4 (Dillenburg & McKerr, 2009a).

Some caregivers minimised their own health problems. Their concern was how their son/daughter was coping.

I've landed in hospital a couple of times. [Name] has to go and stay with some of the family. He doesn't like hospitals, and he won't come and visit. He had a bad experience when he was a child so he just doesn't like it. (Carer 10)

3.2.3 Emotional and physical health issues for sons and daughters with disabilities

Getting a diagnosis for sons or daughters remains a major issue for parent/caregivers (Keenan et al. 2010), as uncertainty will often mean a subsequent delay in accessing services. Three of the sons/daughters had been diagnosed at birth (n=2 with Down's Syndrome; n=1 with birth trauma); 14 sons/daughters were diagnosed before their 7th birthday (average age 3.1 years). Two children had not received a specific diagnosis.

I'm still waiting to be told. They said 'He'll have a diagnosis by 9, we'll be fit to tell you what's wrong with him' and nobody has said yet [that] he comes under any kind of category, literally. He has learning difficulties, he can read some things, he can write his own name but that's the only thing. You know,

he could set up a video, play his games, all these kind of things, and he has a memory like an elephant, but I don't know what category he comes under, they never gave him a category. (Carer 10)

Participants reported general health problems for six (31.6%) of the sons/daughters, two of whom had epilepsy. Otherwise sons/daughters were in good health (Table 6)

I would say she is a bit of a hypochondriac! Walking to school this morning she said she had a cold. Her general health is good apart from her aches and pains. (Carer 9)

Table 6: Parental/caregiver concerns about son/daughter's emotional and physical health

Health issue	Mobility	Communication	Sensory	Behaviour	Diet	General health	Mental health
Number of participants	18	16	16	15	12	6	2

Mobility was a major issue for nearly all sons/daughters (94.7%; n=18), with eight having serious mobility problems, which often result in an increased need for supervision.

Well, inside the house he is fine. He can't use a stick, his coordination is not good for a stick. If he was going down a slope he doesn't realise it and sometimes he falls. Outside on his own is difficult. He has to get to know inside for his orientation. At [university] he had to get to know it, he got lost in the long corridors but somehow managed to get to the lectures. To get there was a big achievement for him. (Carer 8)

He has just recently started to walk, this last week or two he's started to get a little wobbly on his feet. He almost looks like a little drunk person and he's falling about a lot so he's kind of a danger being able to climb up on the sofa and things, but he hasn't the sense to get back down again so you're having to constantly just follow him about. (Carer 14)

He has his independence at home but you have to watch him. We walk behind him on the stairs because of his balance and seizures because they come on that quick. Seizures usually come on first thing in the morning or in the middle of the night so we need to be especially careful around the stairs in the morning times. (Carer 5)

The main concerns, especially with regard to mobility, were the accompanying behavioural issues; 15 of the sons/daughters required constant supervision due to vulnerability, impulsiveness, non-compliance, or lack of safety awareness. These

traits are often associated with ASD, but were reported by the majority of families, including those of sons or daughters with conditions other than autism.

Great walker and great runner, if it's where she wants to go, when she wants to go. It's the social aspect of the autism there, there is no physical disability, we are going down the road for a walk and my daughter thinks 'No we are going to see uncle [name] and I am going to hang a right', and by God does she hang a right. I have used a buggy because only from the point of view I know that it will stop a kick off confrontation, but she loves walking, loves running but on her terms. You just can't take the chance. (Carer 16)

He is good, he is able to get out and about himself but would have to be careful of him going up and down steps, he can trip easily...there would have to be somebody with him at all times, he has no sense of danger, he has no sense when crossing the road- he is a vulnerable young man when he is out and about, money wise, that sort of thing. We just wouldn't risk it, we are trying to increase his independence but somebody has to be with him, I wouldn't let him walk from here to the local shop. (Carer 13)

Other behavioural issues at home were reported for 15 sons/daughters. Most parent/caregivers interpreted these behaviours as undesirable or 'problem' behaviours ranging from temper outbursts (n=6), stubborn or rigid attitudes (n=6) to very challenging behaviours (n=2).

She can be very aggressive, when she gets hyperactive, you know, really, really hyper. She'll nip and punch and hit and bite and kick, you know, she goes into these really strange moods, like throwing themselves on the floor, things across the room, she broke our telly, that's the second one, she slammed into the glass and she broke it. Sometimes it comes on just like that, for no reason, sometimes if she's not happy that you've told her to do something and she doesn't want to do it, she gets annoyed, or she can't get away, like a typical child, lashing out. Sometimes she does it because she's in pain, because [name] doesn't have any verbal communication, no speech, so she tries to get you to do what she wants and I think she gets frustrated. I can understand that, someone says 'Tell me what's wrong' and you can't get the words. (Carer 19)

Parent/caregivers who had undergone training in applied behaviour analysis (ABA) talked about how they had dealt with behaviour problems.

Behavioural issues obviously are the main ones and obviously we've worked on behaviour modification and putting in place things in the house that help with the behaviour and we are fortunate enough in one way because we don't have another child so we can devote the time and even the environment to ease behavioural issues to some extent. (Carer 1)

Table 7 shows the kind of sensory issues sons/daughters had at home (n=16). Seven of these sons/daughters had two or more sensory sensitivities, mainly kinaesthetic and auditory combination (n=5).

Table 7: Sensory issues experienced by sons/daughters

Sensory issue	Auditory	Kinaesthetic	Visual	Olfactory
Number of son/daughters	11	10	2	2

From an early age, noise would be an issue for her, not so much noticeable now, but smells as well, because I think that's the issue with food, she'll come in and she'll smell things that you might not be able to smell. One of the things would be breath, a person's breath. (Carer 14)

Noise is a big issue, he cannot stand things too loud and yet he speaks very loud when he is speaking to you. Things, for example, when he was younger he would scream the whole time being bathed. I though he just hated being bathed but when he got older he told me it stings and hurts his skin and to this day he cannot take a shower. He doesn't like you to touch him. Can't stand getting a haircut and nails cut etc. Doesn't like wet things on his skin therefore won't go out in the rain. (Carer 15)

Almost half (47.4%, n=9) of the sons/daughters had eating problems, mainly restricted variety in their diets or amount of food consumed.

He was actually hospitalized when he was 2 years old and put on tubes down his nose. Not too bad now, he will eat chicken nuggets and chips, and maybe spaghetti, it's a bit more varied now than what it used to be. (Carer 4)

He enjoys his food, and needs a diet, as he is overweight. I think with his medication for his depression as well really has increased his appetite so as a result of that the weight just sort of goes on. (Carer 13)

Two young adult son/daughters had a dual diagnosis, i.e., they had a mental health related diagnosis as well as their primary diagnosis. Another two parents had concerns about their son/daughter's mental health, but this had not been officially diagnosed. Eight families reported other specific concerns, including self stimulatory behaviour ('stimming' such as hand flapping), problems with gag reflex at the dentist, toileting problems, worry about sexual behaviour, sibling jealousy, safety with cooking at home, sleeping problems and mood swings.

Now that he is 21 he has sexual issues. He likes girls with blonde hair. He will rub himself inside his clothes but he goes to his room. He will also get embarrassed if you ask him what he was doing and has the understanding of where it is appropriate. He has never done anything inappropriate, thank goodness. It's a big worry. (Carer 5)

However, some of the parent/caregivers made the point that even when discussing problems, caring for their son/daughter was not at all a negative experience.

We just do things automatically; it's not conveying to us that it is a problem. There is no problem with him. People have met us in the street and said that it was a terrible burden for you, well I say that it is not a burden for us it's a blessing. People don't understand, but we see it like that, as we have been used to it all our lives, it's a matter of fact. (Carer 11)

A friend said to me that I am lucky, and I said 'What do you mean?', and she said the Lord picked you to give you your son, you have big shoulders, I thought it was very nice her saying that. (Carer 12)

3.3 Care within the family

Almost half of the sons/daughters (47.4%, n=9) had limited verbal communication. This made it difficult for parents to gauge the feelings, worries, and needs of their son/daughter and for some this increased concern about family dynamics and functioning.

She can ask for toast, or she can ask to have the DVD put on, I suppose she's about 18 months or 2 years old. If you ever see a little 18-month-old, I always think well, that's what [name] is like, so I think that's about the level she is in most things. She has no way of telling you if she has got a pain. The only way, if she's unwell, she just lies down really then you know she is not well really because she never sits down! (Carer 18)

He has poor speech and we use [name] method. The very sad thing for him is that he understands everything but he just cannot get it verbally out. He can read and write very well but he just can't verbalize things. But he will make his needs known very well, he will draw it out, he will write it out, he will sign it. The saddest part I think for us as parents, because we are great chatters and there is always stuff going around. He is part of it, he is always part of it, but not as big an input as we really hoped he would have. But he understands it all. He is actually very dramatic and would do miming, and do that sort of stuff. He is a character, an absolute character. So he has his ways of communicating. (Carer 13)

However, for most parents, limited verbal communication was not a problem at home, as they had developed alternative ways of communicating. Seven parents reported that

their son/daughter was articulate but did not always communicate effectively, particularly in recounting events or problems, or engaging with people outside the family.

He is still reluctant to speak to anyone he doesn't know, so I might have to e-mail his boss at work, or he won't share information in a meeting so I e-mail his boss. We could spend a whole day at home and there might be only two words - 'Any dinner?' (Carer 3)

3.3.1 Care arrangements within the family: everyday living

The use of modern technology, e.g., televisions, computer games, Internet, and specifically social networking sites, were the most popular activity for most of the sons/daughters (79%, n=15), across the age-groups (from 5 years onwards).

Only six of the sons/daughters (31.6%) engaged in sporting activities; six (31.6%) engaged in imaginative or creative activities, such as reading, art, or jigsaws; four (21%) carried out household tasks, such as baking or vacuum cleaning; and four (21%) engaged in social activities outside the home, such as sleepovers or play dates. Other activities included homework, listening to music, toy play, playing with domestic pets, and exploratory play. However, many of these very 'typical' activities require a considerable level of organisation and planning.

Carer 1 described a typical day as follows:

Well, he has a bit of routine: Immediately he comes in, the uniform is stripped off, and we are working on the uniform being taken off in the bedroom, rather than in the hall as soon as you get in. Then a little sort of down time where he goes up to his bedroom, he now has got imaginative play, and he plays with toys in typical boy fashion, discombobulating bits and so on and it's quite imaginative, it's also practical, like so-and-so is holding something or somebody, or he's taking off their clothing, and a lot of time when he's watching, he'll watch a little TV now, though there was a time when he didn't, although he read the TV guides and was aware of all the programmes but now he'll watch an episode of [name of show], which he didn't used to at all, but again it's a little routine. He's much better now at amusing himself. He spends a lot of time looking through his calendars, and he annotates and draws round the pictures and all sorts of things like that, and he goes swimming. We try and take him swimming every day, or trampolining, or some sort of physical thing like that. Sometimes he'll help with the garden, or feeding the chickens or things like that, or visit my parents. They live very close to us, so that's a nice little thing to do, and he goes on the computer a little bit now. He'll help with setting the table, and clearing the table, he's quite into food, cooking, so he'll present ideas for what we can eat, generally

taken from TV guides, and calendars and recipe books and things. Then we'll try and organise play dates and outings and so on, and now we've got a couple of little after-school things. There's a little disability sport he goes to, but it's only running for five weeks at the moment and then there's riding for the disabled which he goes to one evening a week, so that's nice. There's quite a lot of organising, and a lot of physically being on hand to make that happen. Sometimes I find he can get frustrated or maybe do behaviour that you wouldn't necessarily want, if he is not being occupied or channelled. He is like a younger child, he needs a lot of direction, a lot of observation, a lot of supervision. He likes to go for outings and see things and do things but actually all of that is quite intense.

Carer 8's son had undergone an intensive physical programme to help him walk when he was young, and his mother felt it was equally important to maintain this progress, with their support:

An important part of our lifestyle is to keep up his physical strength. He is swimming and doing some exercises on machines. I have to help him change but once he is in the gym he has his own helper to show him the machines. That is at least once a week after work or at the weekend.

For Carer18, the activities her daughter chose were very limited, but very demanding in terms of time and energy:

She spends most of her time demolishing Sellotape. I buy them in boxes, and sometimes she can do 40. She just rips them. I don't know if it's the sensation, or the noise of it or what it is. That's what she does. Or I'm singing to her, I'm sitting on the chair singing, walking around, if I'm cooking, I'm singing to her just non-stop. The only time she's not getting your attention is after she's had seizures, maybe, when she's quiet but that's the only time. Other than that she's constantly talking, or screaming, I'm constantly singing, talking to her. She used to love mirrors, looking at them and singing at the top of her voice and she repeats the same thing for five and six days at a time. She'd say 'I like it'. She can repeat that maybe for five, six, seven days, just non-stop, but sometimes I don't hear it, you know, if somebody said to me 'What was she saying?' I'd be hard pushed to remember. She can sing all the nursery rhymes, she's got a good tune you know, it's not hard to listen to. From she was about five she's never really advanced any further than that; anything that she did before she was five years old. She hasn't really done anything else; anything she learned before that's about the height of it. That's how she amuses herself.

Even when a son/daughter was able to entertain themselves, participants could not relax, as there was constant need for supervision and at times, distraction from an intense interest.

He is quite happy to potter about and do his own thing. And that is fine, but you have to have an ear out for him. You sort of have to make sure he is not endangering himself, just in case he falls. You listen, you are alert. You don't have to be beside him but you always have to be listening and see what he is doing. (Carer 13)

[Name of child] would spend all his time on his computer on gaming. He has his room set up like an IT centre. He has a massive flat screen TV that acts as a monitor. He has a gaming computer and all the whistles and stops but it is necessary for me to interrupt this world and take him out of it. I need to take him out to come down and have meals to remind him to have a bath, to remind him to do his hair, to make him to Hoover up and make his bed, now, he doesn't do it very well. He has to know there are other things he has to attend too. For instance at the weekend I split the chores between my two children, so as not to make a difference. I sometimes get concerned and remind him that his games are only games and what he has to do away from the games is reality. (Carer 15)

Help from siblings depended largely on the age of the children and their proximity to home. Just under half of the families (44.4%, n=8) reported that other children helped. In six families, siblings looked after or took out a brother or sister with disabilities; in five households, a sibling undertook housework or provided respite.

When they are out and about, when she decides to go out shopping she will ask him if he wants to come with her for a couple of hours, two to three hours, and when she is well enough herself it would be two or three times a week. They will go for a walk together. She will say come on and that's it, and he will do it because he loves being with her. (Carer 13)

Parents used a variety of approaches in attempts to alleviate challenging behaviours and deal with issues of mobility or health. Some used direct intervention while others relied on careful planning and organisation of the day.

Up to this point it's been trial and error, seeing what can work and what doesn't work. There's stuff that definitely doesn't work, and stuff which will work sometimes and not at other times. He gets a warning that such-and-such behaviour is unacceptable and 'right, this is your last warning and there will be consequences, you will go to your room'. I think that is the most effective one, for sometimes he will take heed of that, the bad behaviour will stop. At other times, he'll just ignore it and then he's frogmarched up to his room and throws things for 2 or 3 minutes. Once the tears start you know he's calmed down so you always listen out for the crying, for the tears, then you know that the moment has passed. (Carer 2)

For example if loneliness is an issue I will drop whatever I am doing and we will go out, something that he really likes to do, to the cinema or shopping,

anything to give him that little bit of time. I am always very conscious that the loneliness could be an issue for harming himself. He tends to be slightly obsessed with death and dying and it worries him terribly and I am not qualified to deal with that issue with him and if I try to broach it and say that death is part of life he will say he doesn't want to talk about it. It's an issue that we face in the future. We have never had any support, once [name] was diagnosed that was it. We had no social worker, no one came to check up on him and when I went to the doctor we got nowhere. (Carer 15)

One parent made the choice to leave work in order to cope with the situation at home:

I suppose the only big change for me was leaving employment at the time. [That] was because when she was younger, it was because of her sleeping. She is just a child who doesn't need a lot sleep, but when she was younger it was worse, now she is up to midnight and she will sleep 'till six am. (Carer 6)

Some families undertook specific home-based interventions; three families received intermittent support from statutory agencies, and three parents followed individually tailored intensive behavioural programmes organised by voluntary sector groups.

We began a home-based programmes focusing on Applied Behaviour Analysis [ABA] with the [name] charity and speech therapy and anything else we could get! The best thing about ABA I felt was that it gave me an understanding of the issue involved and also a way to teach. I am a teacher, and here I was faced with a child that I had no idea how to get them to learn, or to get them to focus on me and for any parent or teacher, that's a hugely daunting, scary scenario. It was the best thing that was to give us something to try, even if it hadn't been successful, and I'm very glad to say that it was. But even if it hadn't been, it was something you can do in this situation and that's what it takes in that sort of situation, when your child's diagnosed, it's very scary and they sort of say 'Well here's your diagnosis' and that's all you get. There are very few diagnoses that you actually get where they can't say 'here's the treatment', you know, 'Your child has x, y or z and here's what we're going to do about it'. You don't get that, you get 'hmm, well here it is, good luck'. (Carer 1)

I go to a behavioural therapist [from the Trust] and he gives us wee tips every now and again, but I haven't seen him for nearly a year, we don't hear a lot from him to be honest, we get wee tips, and that's it. (Carer 19)

For mobility problems, one parent used intensive physical therapy and two parents used specialised buggies.

3.3.1.1. Going out with family members

Going out shopping or choosing a suitable place for a holiday were described as

difficult tasks that could divide families and cause distress, both to the children and to the caregivers.

It's a nightmare, even now she's eleven and she would still have a hissy fit in town, when she's not getting her own way, and you're like: 'Oh my God please get me out of here' and of course the more you put your foot down as she gets older, the more she puts her foot down. Holidays for us? We go places but the stress of it. We have only ever had three nights, because she wanted home, the stress of it is just too much. (Carer 6)

Definitely very restricted with normal day to day things like shopping. You're having to squeeze those things in, in the evening, whenever my husband is here I can pop out and do the shopping. We can't do those things, normal family days out, you're doing them because you want to do them for your children but it's not always a success and they'll end up screaming the place down, or not getting their own way, so you always come home feeling a bit deflated. (Carer 14)

For some parent/caregivers anticipating problematic responses caused them to avoid certain situations entirely.

We've had one holiday in 15 years and that had to be at home because we weren't sure how [name] would get on with the climate and I was conscious about his immune system being low, maybe over cautious. The sheer amount of care that [name] needed... you always had to think will there be a bath and not a shower, because he wouldn't have a shower. Would there be facilities that I could care for him and relax him? If he takes a tantrum is that going to impact on other people that would be close by? So we just didn't go anywhere. We used to do daytrips rather than holidays. (Carer 15)

3.3.2 Care arrangements within the extended family

Of the 18 families, only a third (n=6) said they found their immediate or extended family a source of support, whether financially, practically or emotionally. Three carers had in fact taken on caring for other relatives as well as looking after their own son/daughter with disabilities, and in one instance, the breakdown of her spouse meant that a participant was caring for three people. In some cases the wider family were unwilling or unable to help and some relatives seemed to create problems due to lack of support.

Our family as a whole, we are not a very tight knit family, so the only support we really have is ourselves, because our family really didn't want, not that they didn't want to get involved, they just didn't get involved, so we did our own thing... we did it ourselves. (Carer 13)

Especially in the early days when I was trying to tell everyone there was something wrong with my child. I didn't know if they didn't think there was or were hoping there wasn't but there was that conflict. It was a lack of understanding. That was a big problem. There was also another problem with other not so close family members, cousins that I would have been quite close with, who would have come and visited us all the time and when we got [name] diagnosis they just stopped. I think that possibly because at that time his behaviour wasn't great they probably didn't know how to cope and just withdrew. They haven't been over my door now for about 15 or 16 years. It hurt a lot. (Carer 17)

I remember taking her home when she was about 5 and my father - she was doing something; running was the main thing, and screaming, and one of my cousins came in and he said 'This is [Carer 18's] little girl but, really, she can't manage her that well.' I've very little family support, and I be crying sometimes, but nobody wants to listen to you really, they go on to tell you how difficult somebody else is, and that's not really what you want; not at that particular time... I say 'I don't want pity', but really, I do! I want somebody to say 'Oh, you poor thing!' (Carer 18)

For some, health or location restricted family support in a practical sense or even placed additional stress on parent/caregivers.

My own situation was such that my mother had died when I was 18 and my father was quite elderly. My sister as well, she is a nurse and did shift work so she wasn't available for me either, so I didn't have that back up and then my husband's family is from England. I had very little family support. (Carer 17)

Where families were able to provide support it was experienced like a 'lifeline' without which coping would have been very much more difficult.

My father died, my mother lived until she was 92 and my mother-in-law too, they both helped as much as they could, until they themselves had to be helped. (Carer 8)

3.4 Care arrangements outside the family

For most families, relationships and support outside the family, whether from friends or professionals, were considered very important.

3.4.1 Friends and neighbourhood

Some parent/caregivers carefully organised their own and their child's social life to encourage friendships and social skills.

I strongly supported friendships, having parties at my house on Halloween. He always had friends. I regarded that as my main task. It was not an easy task. I worked part time all the time as well. Our social circles were through our local small community. But all the time my focus was on [name] specialised upbringing; to do things the way that would further his development and not hold him back. (Carer 8)

Some of the participants described the difficulties of their personal social isolation, specifically in contrast with the lives of friends, neighbours, and others.

I would say for the last 10 years we kind of didn't have friends over much at all, when [name] was a bit younger maybe, when he was very young, really before he was diagnosed we were kind of doing 'Oh, we have a baby' because everybody had babies. I mean most of my friends had babies at the same time and then as paths diverged, and as what he could cope with, and how their children developed and coped with him diverged. Only recently, as he improved and is able to accept people coming into the home, you know, cope with that and he is able to go out more and meet people, we've begun to reclaim a little bit of that and our friends. You just kind of have to say well, we'll just accept this is the way you do this, or you'll go mad. (Carer 1)

It's just that I'm very isolated with [name]. It's not really that they don't care, they do, but what can they do? My point is, they could come and visit me, now and again, just for an hour and put up with [name] screaming, but they don't. They feel uncomfortable because they feel you can't really talk when she's around, apart from screaming she sings at the top of her voice so nobody else can hear their ears. I just say I'm the only mother of a 40- year-old who still knows every nursery rhyme going! (Carer 18)

3.4.2 Accessing services and support

The majority of families accessed a range of services and support, although not all did so on a regular basis. Support needs varied across the life course, depending on both ongoing and crisis situations at home.

3.4.2.1 Services and support from Health and Social care professionals

Table 8 outlines key professional contacts for parent/caregivers. For the majority of individuals (52.6%, n=10) social workers were the main contact for parent/carers accessing services. Over a quarter of individuals (26.3%, n=5) were not directly or regularly accessing health and social care services, and parents did not have a key contact, in two instances this was in part because of inadequacies in the communications between providers and families

Table 8: Key contact for services

Professional	Social worker	GP/ paediatrician	Nurse	Other	None
Number of participants	10	2	2	0	5

N=19 sons and daughters

We had a psychiatric nurse until recently, but with the cuts that has stopped. [Name] was very seriously mentally ill, and you should have a CPN² five years, but they got sick and they were off for six months and there was not enough staff to replace them. We have no key worker now. We did have a social worker, from he was 3 until he was 26, and then he went into hospital. (Carer 3)

Six of the families had received occupational or housing support to adapt their homes, ranging from substantial changes, such as a garage conversion and installation of lifts, to the fitting of bathroom appliances and the acquisition of specialist equipment. Four of the families were enquiring about adaptations. For the most part, parent/caregivers were satisfied that the adaptations were helping as anticipated.

Of the 18 participating families, 13 (72.3%) reported that they had access to services or support. While four (22.2%) of these families used direct payments for the care provided, only four had a full Carer's Assessment. In fact, one third (n=6) of the participants were either unclear or unaware about the need for a Carer's Assessment.

I don't know if we have had a Carer's Assessment, I don't think so, what does that entail? A girl did come out because when I was ill, I was worried about my wife. The neighbours were very good and were very helpful with doing shopping and other things. The social worker came out and asked did we need anything. We said 'no', as we help each other and she asked about food, and I said that meals might be handy. She said that she can arrange for meals for 'you and your wife'. I asked about our son. She said, 'Your son would have to pay, because you would have to see them in [name of other Trust].' I said just to forget about it as it wasn't worth it. (Carer 12)

Ten of the families had positive comments regarding services and support, including flexibility of the services (n=5), trust and confidence (n=4) and getting a break (n=3). All those receiving direct payments stressed the flexibility this gave them.

² Community Psychiatric Nurse

The flexibility gives me a life. I'm in charge instead of at the behest of a domiciliary service who ring at the last minute. I can 'bank' hours, so I can use them in a crisis, when I had surgery, I had someone 24/7, there's no way you'd have had that within the old system of domiciliary care! (Carer 3)

Three families mentioned negative aspects of contact with professionals, two of which related to communication problems.

The transition is a completely different kettle of fish into adult services as I am finding out and has been complicated by the fact that the social worker is on sick leave and the paperwork hasn't been done and the worry about [name's] placement once he finishes school in a year and a half, nothing has been done about that at all. (Carer 17)

3.4.2.2 Holidays and using respite/short breaks services

Holidays needed much more organisation than for other families, and sometimes couples had to take their breaks separately.

You have to plan things. I would take holidays with mates and my wife would too but it has to be planned far ahead. He still doesn't like it but you have to have some sort of outlet. It's only for a few days. We get away together as a family but it's not really a holiday you're still doing the caring. We've got a wee caravan and we're away every other weekend. (Carer 5)

He doesn't like the sun shining and doesn't like travelling, he doesn't like strange faces, he likes a routine of things, he likes to know where he is and what he is doing. We always made a point of taking him out everywhere and going out socially with us, but again you were always aware of people watching at times and that sort of thing, and that is a problem. It's not our problem but still you are aware of people just looking, but we always made sure that he was part of the world like everybody else. He deserves to be, so why not? (Carer 13)

As sons and daughters grew older, some families travelled abroad.

We were told we wouldn't get him over 5 years of age, as there is a high mortality rate amongst the children. Well, we couldn't go on holidays, his chest was bad he had a lot of illnesses when he was young. We took these in our stride. 12 years ago we brought him to Disney World, as we didn't know what way things were going to be. He believes Mickey Mouse is real, he loved it. Since then he's been everywhere. (Carer 11)

Table 9 shows that more than half the families (55.6%, n=10) had used some form of care provided by others in the previous 12 months, ranging from two hours of sitting services to two days per week in a residential setting.

Although the specific services offered by statutory agencies were officially referred to as ‘short breaks’, all the participants referred to this provision as ‘respite’. As such these terms are used interchangeably. Respite or short breaks within the Health and Social care services are defined as ‘*short-term, temporary relief to those who are caring for others, it is any activity or service of limited duration designed to provide a break for a dependent person and their carer/family from the usual routine*’ (Patient and Client Council 2011, 6).

Table 9: Care or sitting services utilised by parent/caregivers in the last 12 months

Services	Number of families	Paying for some of this service
Respite	10	4
Informal care	9	3
After-school	6	3
Holiday scheme	5	5
Adult education or day care	3	0
Unregistered childminder	1	1
Registered childminder	0	0
Home child carer	0	0
Other	6	5

Most families had incurred some cost for these services, with the exception of adult education, day care, and respite provided by the local HSC Trust, which were free to the end user. ‘Others’ included organised and regular social outings. Four of the families used direct payments to provide specialist support for their children.

Well now they give me direct payments to pay [carer's name] to do it. They give you the money, but you see it's very easy for the Health Boards now to give you the money to do this, but you have to find somebody to help. I have tried to get people to help me with [name] and I've had one or two, and they've never come back. [Carer's name] is brilliant now but I couldn't leave her in the house with her. She can take her out in the car. She spends about 10 hours a week driving her in the car. The other 10 is taken up with her going back and forward maybe to take her back to [respite] maybe on a Sunday. (Carer 18)

Costs incurred by parent/caregiver also varied, from £1 per session for a Saturday club to £15 per morning for a Summer Scheme. In general, respite schemes for children organised through the Trusts were free, except for associated costs, but this changed when the child transferred to adult services. Adults using respite had to pay a

proportion of the cost, although in some instances this was met through direct payments. Two carers did not engage with statutory services and used direct payments to organise individualised support; four families did not use any care services provided by Trusts. For some, lack of available services led them to manage by themselves.

We have been fighting for years for respite, with all the cutbacks. He wouldn't go anyway. It would be beneficial for carers to be trained, and then people are loath to bring strangers into their home, unless they are related to some government organization. (Carer 11)

3.4.2.3 Peer support and caregiver organisations

Eleven (55%) parent/caregivers belonged to caregiver organisations; four (20%) of these belonged to one group, three (15%) belonged to two groups, and four parent/caregivers (20%) belonged to more than three groups. Nine of the parent/caregivers (45%) did not belong to any caregiver support group.

I joined [name of group] so I got the holidays, you know, and I got the days out and the nights out with the group. I'd have gone out with them some Saturday nights and that's one thing the weans were very good about. 'Away you go out, mammy, we're all right here'. (Carer 10)

Those who belonged to three or more groups all had children with autism, and the increasing number of autism-related organisations may in part account for this figure. Notably, over half of the carers who felt the attitudes of their wider families had been affected negatively by disability issues at home did not belong to a carer's group. Some felt there were no groups that suited their circumstances.

We did attend [name of group] but the meetings weren't really any benefit. It was mostly people with kids with Asperger's. [Name of son] has autism and learning difficulties combined, so he is a lot more difficult. (Carer 5)

There's an autism group, a Down's Syndrome group, there's nothing for his disability that I know of. (Carer 10)

Four parents were actively involved at committee or policy level with disability support groups, and two had founded groups themselves. One caregiver was currently involved in setting up a group for parents and also one for children with disabilities in her local area, facilitated by a national charity.

3.4.2.4 Social opportunities for sons and daughters

Creating social opportunities, such as establishing friendships and social networks, was viewed as an important facet of growing up and becoming independent. It was considered more difficult for young adults with disabilities to meet with peers in social settings and networks. The parents of 14 (77.8%) children and young people felt that their families had missed out on social activities. Four families felt that their children had not missed out; however, these parents had planned and organised their sons/daughters' lives to make the most of available opportunities.

He likes being out and about, he loves the park, he would go every day... and he likes going out on his bike, we go off the two of us just, and most weekends we go up to [name of shopping centre] he likes shopping... and running about, he's started football there a couple of weeks ago, a football club but unfortunately I think his expectations weren't matched by the reality, really.
(Carer 2)

Those families who felt their children had missed out on social opportunities felt this was due to a number of factors; among the reasons given were three who felt they were too expensive, three who had transport problems, seven who could not take part due to health issues, 12 who did not take part because of challenging behaviours and three for unspecified reasons. The parent/caregivers also believed the lack of specialist support was a factor.

She would have needed one to one supervision or she would just do a runner, I mean summer schemes, we have so many churches and they all ran wonderful summer schemes and [names of siblings] went and I had no qualms, and they were only ten years of age but they could cross the road and come back home, where I could meet them at three o'clock and wave them across the road, I couldn't even do that with her, so, yes, it is the lack of that infrastructure that she needs. (Carer 16)

Specialist staff training was of particular importance when medical issues were also involved.

[Name of son]'s epilepsy medication is difficult to administer if people aren't trained in how to manage it. He has grown quite a lot recently, so he keeps 'growing' his dose of medication, so as it happens this year he's on 45 ml a day, so he gets 10 ml in the morning, 10 ml at lunchtime, 10 ml in the afternoon and 10 in the evening, no sorry, 15 at night before he goes to bed.
(Carer 7)

Lack of transport and level of expense were obstacles, the former because the main carer either did not drive or could not always be available. Some families found that

suitable activities were just not available locally, especially for older adults with disabilities.

Oh undoubtedly, [since he grew older] he misses out on things, he went to the [name] club, on a Friday night. He didn't want to go back. He didn't want to mix with young children. He packed it in a lot of years ago. (Carer 11)

3.4.3 Education, work and training for sons and daughters

Of the 19 children, the majority (63.2%, n=12) were under 18 years of age. Ten children were in school, three in mainstream and seven in special schools, while one adolescent was attending a Further Education college. One child was under school age, but – much to his mother's distress- no pre-school placement was currently available although there had been concerns about his developmental delay for some time.

We're waiting for the finalised Statement for a special needs school. Well, I had been round well over a year ago looking, and I had made it clear to [nursery at school] and the Education Board that I was really keen to get him in there, and then the Statement would have began sort of around the Spring time and it's just basically taken that length of time...I've been told it could be July before I even know...and he'll be three and a half by then. (Carer 14).

Two young men had university degrees; one of them worked full-time in a government supported placement, while the other worked part-time in a voluntary placement. Two other young men were employed part-time in work associated with an adult centre (one statutory, one a drop-in base organised by a voluntary group), and attended the centres for the remainder of the working week. Of the remaining three adults, one attended a social education centre full-time, one attended a day centre part-time and one had made the choice (with parental support) to stay at home:

No, what happened was whenever he took that first [illness] when he came out [of hospital] he went to a day centre. I retired at 62 and he said he was retiring too. (Carer 11)

When he was at [the centre] he would come back and his clothes would be soaking with working on the woodwork and the sawdust would affect his chest. (Carer 12)

Parents in general were determined to get the most suitable placement for their children. Eight families had undertaken the arrangements themselves (that is, for three work placements and five school or college placements) rather than relying on

statutory assistance. Of these parents, one had helped form a community action group when told there was no day centre place available for any school leavers in her area and one had taken her Education and Library Board to a Tribunal when her parental choice of school was overruled, although ultimately she was unsuccessful.

We lobbied, and I went ...were they MLAs then... but nothing could be done, and then [political party], and nothing... so I wrote a letter to the Council ... so it went on the Agenda, and the newspaper gets a copy of the Agenda so a wee fella from [local paper] phones me and asks to come down and see me because he'd like to do a bit on this... it was about fighting to get your child into the adult centre... that was fine, I was on BBC1 and Ulster TV on the same night on both channels, me and other parents we were all fighting for our kids to get a place, we were up at Stormont I don't know how many times, we got in touch with [name of another politician] and he met with us and we talked about the problem... they let them open up what they called a satellite. (Carer 10)

I thought right, I have parental choice, they told me I had parental choice and I put down [name of school] and that's where I wanted her to go and of course it came back and said no, she would go to [other school] and I thought, where is the parental choice there? You know I took them to tribunal and she did go to [other school]... but you know it was that equality issue again. (Carer 10)

Nine of the placements were not considered close to home, requiring a bus, car or taxi journey and this in turn required additional parental organisation, which could be demanding and time consuming.

There is a bus to bring him in and out however it doesn't come until 10.30am so my wife brings him in. The bus is there though if she cannot drive him for some reason. He goes home on the bus every day. (Carer 5)

Various distances but has to be close enough to be collected every day, various locations of [job]. I used to take him myself and collect him but my husband since he has retired has taken it over which is a great help to me. We also used a taxi quite often, by an approved taxi company through the scheme. We can do it ourselves and it is more convenient sometimes. There is only so much the budget allows. (Carer 8)

Well I do the mornings and [helper] does the afternoons... now they give me direct payments to pay [helper] to do it so they don't expect me to do it for nothing, but even so it takes up a lot of your time and you shouldn't have to do that...you know, they should supply transport. They give you the money... but you see it's very easy for the Health Boards now, or whatever they are, to give you the money to do this, but you have to find somebody to help... I have tried to get people to help me with [daughter] and there isn't one

person who... I've had one or two, and they've never come back. (Carer18)

3.4.3.1 Parental satisfaction with placements

Of the 17 placements reported, the majority of parents (70.5%, n=12) felt they were addressing the academic requirements of their children. Of the others, one parent felt there was very little feedback with which to judge her child's progress and one parent believed her son was working below his level of ability.

I feel that there's not an awful lot of communication between me and the school. At the beginning of P2 I asked if we could do a diary between each other and it was refused... and then I phoned the Education Psychologist and she was quite annoyed about it, and she must have said something because then all of a sudden I got the diary home, which is just really if she's had a good day... there's days that they forget, which is fair enough when I know they're busy, but the only time I get to know how she's doing is on the parent interviews, like everybody else. (Carer 14)

Well the work that he is doing is routine work. He couldn't do the work that is up to his intellectual abilities. He makes up for it with outside activities. (Carer 8)

Two parents of young adults felt their children had very limited academic potential and did not expect the placement to address this.

I mean, there's nothing really you can teach [name] any more, but you know they take them out a lot, they do different...if she's not, you know, too bad she'll be painting and things like that and so, I have to say they are really good...well she's not really interested [in reading]- she used to be when she was younger but not anymore, you know, she'd just rip them up.... I would read her a story but she only likes one story, and that's Madeline...I know it off by heart! (Carer 18)

One parent felt both her daughter's learning disability and behaviour in school prevented her from learning effectively.

Because of her learning difficulties, she can't, she will match things up, the PECs, she will do stuff like that, and puzzles, things like that, but I think they just started doing counting and things like that with her, but [name], sometimes she goes through stages in school, she jumps from one thing to another, she'll do one thing, then she'll not want to do it any more...she jumps and does something else, she can't stay on a single task. (Carer 19)

In general, schools and placements were considered more effective at building social skills, regarded as satisfactory for 88.2 % (n=15) of children.

Yes I think it is. There is a girl in the same class and I notice when I come to pick him up she and [name] are always standing talking. And recently there is a little group of a couple of guys and he seems quite happy with that. I did tell him that when you go to college its different from school and you will feel more like an adult and be able to relate more because the people in your class are doing the same things that you like to do, and have that common bond. (Carer 15).

One parent- while happy with the level of social inclusion in school- felt more could be done outside school hours.

Within the confines of what they have to do on a daily basis, but I think where she misses out is the extra curricular activities the other children would have. School finishes, and she is home at 3 o'clock on the dot. It's social, emotional, physical release outside of that and I think that's what's missing. Happy enough in school with what they are legally obliged to do, but outside of that- nothing. (Carer 16).

Of the two parents who could not say the placement was addressing social skills adequately, both reported lack of communication with the school, which in the case of Carer 4, was compounded by the distance, a 26-mile round trip from home.

I don't get down to the school to talk to the teachers... I don't get talking to any of the parents. I know them to see, but I don't get down to see anyone. I know that they have Scouts and Girl Guides, but I can't drive and it is so far away, and I can't take him to it. (Carer 4)

Again, I don't know, it's very hard to approach them on these subjects, I feel they get...very... get their backs up when you ask what's being done... and I do think you have to be a bit more forward, when it's your child and they're going the whole way through the school system. (Carer 14)

In terms of addressing life skills, a somewhat lower proportion (64.7%, n=11) of children received what parents considered adequate preparation for independent living, which covered a range of everyday activities.

They do cookery. They go on outings. I have asked my daughter about going on public transport, to go on the bus, and I would be there to watch her but she said no. She will have to learn because next year she will be going to Tech one day per week. They will go out with her and get her in to the way of it. (Carer 9)

I have to send him in a list of what he's to get, he goes round the shop, they go with him but he knows what it is he has to get, you know ... the money end he's not very good at, they have to stay with him for that, that's showing him how to deal with money. They cook and bake on a Friday... they do a lot of interaction, taking them up the town and letting them go round the shops and they even went to the bother of getting a bus pass... what the idea was, she was going to take them all down to [different town], to do shopping, just for the novelty of getting on and off the bus... at the moment he's on a programme for showering where the Occupational Therapist comes down, and puts him in the shower... one of the girls made him wee cards where he knows where to start on his hair, and he has that hung up in the shower...so he knows where he has to be... (Carer 10)

For some parents support in this area would make a real difference to family life and to a child's self esteem.

He got teased by a few people [at youth group] because he's not out of nappies... They make them brush their teeth, that's about it, that's all I know ... on another issue, he's 13 and I am still showering him, and I find that, you know sort of...I'd like him to be a bit more independent, to be able to wash himself. (Carer 4)

Well we've tried all that but she doesn't ... they sit her on the toilet when they change her and that, and sometimes she'll go but ...she's doubly incontinent. (Carer 18)

3.5 Health and social care: service evaluation

Ten of the 14 participants who used health and social care services were satisfied with the quality of the services received. However, some expressed specific concerns around service and safety issues:

He went one weekend and they went to absolutely nothing, and I complained. It's a waste of time. There was another [incident], he woke up about 3 or 4 o'clock in the morning, and he got up and walked out through the front door! And only one of the alarms went off. He got to the top of the hill and realised he didn't really know where he was going, so he came back down again. I was terrified! Then another time he complained to me about some boy down in the

home just coming into the bedroom with him in the middle of the night, so I said 'Did you not tell anybody' and of course he said no. (Carer 10)

Half of the families who used caring services (n=7) were satisfied with the duration of care. Over a quarter (28.6%, n=4) had concerns around parental choices with regard to timing of respite, while 21.4% (n=3) stated that they would prefer longer periods of respite care for their children. Respite /short breaks were welcomed by those who used them, seeing benefits both for their children and for themselves. A number of the parent/caregivers (35.7%, n=5) felt that respite allowed them some personal time. One parent mentioned the dual benefits for her child and for her family.

He loves it, and he has a great time and he spends time with other children. He goes on outings with them. It's very important to develop those skills with people other than his parents, so it has benefited all of us. (Carer 1)

A number of reasons were given for not using specific care services (Table 10). Practical issues, such as inflexibility with regard to arranging and timing of care services were the main reasons, however, lack of quality also featured highly.

Table 10: Reasons for not using care services

Reason given	Inflexible, poor timing	Poor quality	Poor training	Too expensive	Care themselves	Nothing available
Number of participants	8	7	3	2	3	2

I'd have felt the child carers may not have been trained in special needs, which has been the case in the past. I always felt [name] might be a bit of a liability, maybe his behaviour might kick off when he was in that environment when he wasn't familiar with. We did try once and found [name] walking towards the road and that really put me off. He had come out of the house and the lady was busy with the other kids and didn't notice. (Carer 7)

A number of families identified issues of concern at home. Table 11 compares issues that affected uptake of services with issues experienced at home. Clearly, issues at home were not always the same as concerns in terms of accessing childcare. Except for health and mental health, all other concerns at home did not affect uptake of services to the same extent.

Table 11: Concerns at home and issues in accessing care

Concern/ Issue	Mobility/ supervision	Sensory	Communi- cation	Challenge Behaviour	Diet	Health	Mental health	Other
At home (n)	18	16	16	15	12	6	2	0
Service/ care (n)	7	9	8	5	6	6	2	1

Mobility and supervision, sensory, communication, and behaviour problems as well as diet were major concerns for most families at home but fewer families considered these as concerns in terms of accessing care services, except for worry about adequate supervision of very active, impulsive sons/daughters or quite specific individual issues with diet or communication.

She's different if she's in respite because it's a different place. They have more time to give her, whereas we have another child to look after. But at the same time she's still hyperactive. (Carer 20)

When I told the new respite service [name] was a vegetarian they nearly had a heart attack because he was the first vegetarian. But it is all good, now. (Carer 17)

Table 12 shows that most participants had requirements for help and advice in a number of areas, including respite, personal care, behavioural issues, general psychological support and help with physiological and speech and language problems and co-ordination of services.

Table 12: Advice and information requirements

Advice/ information	Respite	Personal care	Behaviour	Psychology	Physiotherapy	Speech/ language	Service coordination
Participants (n)	3	3	2	2	2	1	1

It was very difficult, we felt very much alone, and we had to do it ourselves. And then when you actually begin to understand that people with a learning disability have a very high percentage of mental illness. Nobody tells you about because there is a big enough stigma about mental illness within the mainstream of society, but when it comes to people with a learning disability, people just don't want to know. (Carer 13)

I think someone providing an overview for those things would have been a help. I was able to do that myself but then I am a trained teacher and I have the time and the financial ability to do that. I wasn't coping with other

children or going out to work. If it hadn't been put in place I shudder to think what the situation would be now. (Carer 1)

Many participants had undertaken some kind of training or were involved in ongoing training programmes (Table 13). The most frequently used training related to behavioural issues and was either based on short courses, intensive programme supervision, or advice, mostly delivered by a voluntary group, with some training delivered by Trusts and the Department of Education. One parent had travelled abroad to receive training in an intensive physiotherapy programme.

Table 13: Training for parent/caregivers

Training	Provided by	N
No specific training	n/a	5
Short course on behaviour issues	Charity Group and Dept Education	4
Intensive behavioural programme	Charity Group	3
Behavioural advice	Trust	2
Speech and language therapy	Trust	2
Epilepsy training	Trust	1
General autism awareness	Trust	1
Intensive physiotherapy programme	Institute abroad	1
General physiotherapy training	Trust	1

I have pages and pages of courses over the years. I am self-taught and I do a lot of research, so I am as competent as any professional in the field because I can't wait for them to get up to speed. I often deal with mental health crises and the out of hours doctors don't do autism. I have to be my son's physician and advocate. (Carer 3)

All that kind of thing, and just from going on different courses through [name of voluntary group] as well, I've just got various ideas about how to make up my own schedules and different ways of working around the behaviour.
(Carer 14)

3.5.1 The ideal care and support system: the parent's view

Table 14 shows parent/caregivers view of the ideal system of childcare/support. Social and activity provision was mentioned most frequently, including respite and short breaks, afterschool provision, home sitting and social activities. Help with personal care or simply a 'listening ear' was also considered part of an ideal system of support.

Table 14: Parent/caregivers view of the ideal system of childcare/support

Ideal care support	Number of participants
More respite	4
Afterschool	3
Network of trained/aware support	2
Home care/sitting	2
Social/sporting activities	2
Personal care	2
'Listening ear'	2
Direct payments support	1
Early intervention	1
Housework	1
Summer activities provision	1
Transition services	1
More day-care	1
Happy with present level of support	3

There is very little for children like my daughter to get involved in. There are other groups that are mixed but when children are not taught about children with disabilities they can be quite nasty. I would like to see more special needs support, clubs and things. (Carer 9)

We have never pushed for help or anything as we have worked everything ourselves. I have been to conferences and they tell you to make sure that you apply for all these things as there are millions of pounds lying there unused. You have to fight for it and if you are turned down you have to appeal it. It goes on and on, it seem that the government just says 'No'. Some girl and fellow sitting in a government department, it's like 'black is black and white is white'. They don't understand the problems arising in families. They just tick you off and say that it doesn't meet the criteria. We have had to fight for anything we have got. (Carer 11)

Most participants thought that improvements in the system of care would have a positive impact on family life, in particular to allow them to undertake study or training, or enter employment or increase from part-time to full-time employment (Table 15).

I used to look after disabled adults. I would like to do that again. I had to leave work because my daughter had a lot of appointments. (Carer 9)

Table 15: How would the ‘ideal system’ improve your lives?

Improvements	N of participants
Opportunity to undertake study or training	12
Opportunity to enter/increase employment	10*
More time with other family members	10
More time for leisure pursuits	10
More time to spend with other children	6**
Other	6

* n/a for 3 participants who were above retirement age ** n/a for 2 families who had only one child

It would also allow them to spend more time with other family members or follow leisure pursuits and spend more time with other children in the family.

Our daughter lives a bit away, so when we visit we have to leave with [name] if he becomes disruptive. More respite hours would allow more time with our daughter. (Carer 5)

We would love to go out and make friends. At the moment we don’t have any friends, we don’t have a social life, we don’t have a life, this is our life here, our world. (Carers 19 & 20)

3.6 Family finances

The majority of parent/caregivers (72.2%; n=13) felt that having a child with disabilities affected their family financially. Only three (15%) were in full-time employment; three (15%) were employed part-time; three (15%) were retired; two (10%) were students; and nine (45%) were unemployed. All of the sons/daughters were in receipt of Disability Living Allowance (DLA), 15 (79%) received both care and mobility components and four received DLA care component only, although applying for this benefit was seen as difficult or confusing by seven parent/caregivers (39%), who needed help filling in the forms.

Then, you had to fill in his form every three years and it’s like an encyclopaedia, filling in those forms, they’re desperate so I sent it up to get it signed and [the GP] signed it and filled it up for me so I said, it’s not for me, would you fill in the form for [name] and he said, ‘How often do you fill this in?’ and I said, ‘Every three years’, ‘Huh, we’ll see about that’. So he sent away the thing, and filled in whatever he had to fill in and must have sent a letter with it and I got a letter saying I would not have to be filling in any more forms. He has got it indefinitely which helps because those forms, it’s a curse. (Carer 10)

We actually got help at the end after a vast struggle with DSS, one of their officers came to the house and filled in the forms for us, which was very nice

but that took a wrangling of about six months, because our benefits were stopped without telling us, that was about 4- 5 yrs ago, and after numerous phone calls they came to the house and filled in the forms. (Carer 13)

It was particularly difficult for parent/caregivers who worked irregular part-time hours or who had more complex caring situations.

I did have problems as I work part-time, with no set hours and how you inform them of your work, sometimes quarterly, or over a year, changes from year to year depending on adjudication. If you work for three months they will close it and you will have to re-apply and the paperwork, five full pages, makes it that you go ‘Why would I even bother working with the grief this causes you?’ (Carer 3)

Only 11 (61%) respondents received Carer’s Allowance, which depends on parental circumstances. Carer’s Allowance is means tested and age related, and requires an application that is separate from DLA, which relates to the circumstance of the dependant.

They take [Carer’s Allowance] off you when you are 60. They give you a supplement now when you get to 60. It’s half of the Carer’s Allowance. So the day I was 59, I got Carer’s Allowance, and the day I was 60 I didn’t, for the same job. (Carer 18)

Lack of awareness of benefits was a problem for some of the carers who only learned about Carer’s Allowance several years after they had been awarded DLA.

I only found out about that recently, I just assumed you’d have been told about that at the same time as Disability [Living Allowance]. (Carer 14)

Some of the participants were not aware of the difference between DLA and Carer’s Allowance. The letter parents receive regarding DLA was viewed as unclear and confusing with regard to whose circumstances are assessed, caregiver or dependant (for an example of such a letter, see Appendix 3). Four families (22.2%) received direct payments³ to provide services and for them, this allowed flexibility in the type and duration of support.

³ ‘Direct payments are local Trust payments available for anyone who has been assessed as needing help from social services. Caregivers aged 16 or over can apply’. See the website <http://www.nidirect.gov.uk/index/information-and-services/caring-for-someone/money-matters/direct-payments-for-carers.htm>

This pays for a 'personal assistant' for [name]. The only problem is the financial paperwork. The flexibility gives me a life; I'm in charge instead of at the behest of a domiciliary service who ring at the last minute. I can 'bank' hours so I can use them in a crisis. When I had surgery, I had someone 24/7. There's no way you'd have had that within the old system of domiciliary care! (Carer 3)

However, direct payments can be difficult to administer and manage especially for parent/caregivers with few community networks or with dependants who exhibit challenging behaviour:

Some people don't like that because you have to keep the books on it and they would take tax off the other person. I tried to talk to my wife, we are not getting any younger and starting to do all this housework ourselves. I had said to the wife that we would even try and get someone in for a few hours a week to do the dusting and the wife wouldn't have it, but there might come a time when we might have to do this. (Carer 11)

Five families reported that their children received other benefits. Three received Incapacity Benefit⁴, one was in receipt of a yearly grant from a national family support charity and one received Access to Work ⁵benefit.

Two-thirds of families (n=12) reported worrying about their financial situation more than occasionally, with more than a quarter of these (27.8%, n=5) worrying constantly. Of those who reported worrying about finances all the time, four were married couples with children under 18 years of age, where at least one of the partners was unemployed. The fifth carer was a single parent who was working full-time, but whose job was intermittently part-time.

Having been a family carer for 29 years, caring for five family members, I learnt to reduce the stress of financial worry by saving on a regular basis,

⁴ Incapacity Benefit is paid to those unable to work because of illness or disability (before 31 January 2011). See http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Illorinjured/DG_10018913

⁵ 'Access to Work (NI) is available to overcome the practical problems caused by disability. It offers advice and help in a flexible way that can be tailored to suit the needs of an individual in a particular job, or getting to and from work'. See: <http://www.nidirect.gov.uk/index/information-and-services/people-with-disabilities>

taking limited family holidays. There were terrible pressures when [name of ex-husband] became brain injured and no salary coming in. We claimed every benefit, shopped for food at its sell by date and in charity shops. We made major savings all the time. That's the unpredictability of [mental health] disability. You go from one person earning to a position where there is no money coming in and benefits change. You're in the deep end, with no control. I have put money away to maintain stability, if [name of son] wasn't able to earn, or if I got ill, that we can survive. I'm future-proofing the mental health of my family. (Carer 3)

3.7 The future

Parents were concerned both about the personal and family issues involved in growing older while caring for a son or daughter, and also the wider implications of social attitudes towards people with disabilities.

3.7.1 Changing attitudes

All of the parent/caregivers felt that there was more awareness of disability issues in the general population nowadays.

Yeah, perhaps there is a growing awareness or trend and perhaps the more things there are, the more awareness people have. I think one of the most difficult things about autism is because it's primarily about behavioural issues. Your child can be seen initially like they are typically developing so something that is very distressing for your child, other people won't necessarily understand why they behave that way because there's no physical cue for. There was a time when [name] broke his leg and was in a wheelchair, and actually that was an easier summer for us as parents. It was easier because you were able to take him places and people were more accommodating because you had this big visual cue: 'Special needs coming through here!' (Carer 1)

However, six carers qualified their statements by saying that there was need for improvement with regard to the attitudes in the general population.

I can see in the last 17 years it has improved, but I wouldn't say there has been that much more acceptance, they are aware of it more but I wouldn't say they accept it any better. (Carer 15)

Because of the DDA6, section 75 and carers services all that legislation is there now, but it doesn't totally deliver more awareness. (Carer 3)

Fifteen families (83.3%) felt that government organisations had a more positive attitude towards children and adults with disabilities, in part because of a greater awareness of rights on behalf of the parents. However, these changes were not always shown in better service delivery, or in a ‘joined-up’ approach between agencies.

There’s possibly an awareness, but nothing to back it up, really, nothing to follow on. I’m not blaming anyone, but even when your child gets a diagnosis, you’re really just left to it from then on. There’s maybe just a note written on a piece of paper, I don’t understand why they can’t put together a sheet of resources or contacts to give each parent and keep it consistent, you know? For people who aren’t pro-active, they’re really going to find it difficult to know where to go from there. (Carer 14)

Government attitudes towards disability can be quite an ad hoc approach, or it’s not always done for the right reasons. You almost get the impression sometimes, that the attitude is governed by financial reasons or lobby groups. It doesn’t seem very joined up a lot of the time. (Carer 2)

Where children’s services have been seen to improve, this may not necessarily be the case when they make the transition to adult services.

They regard disabilities very seriously now. The earlier attitude that the school had has changed greatly. Young parents of today nearly get too much help. It is nearly bad for them because they feel too comfortable but it makes them forget that it only gets harder later when the child becomes an adult. (Carer 8)

3.7.2 Growing older

The issues that worried parent/caregivers most about growing older were their own health (n=6); their son/daughter’s condition (n=4); living arrangements for their son/daughter in the future (n=4); lack of resources and knowledge (n=2). Two parents did not specify their worries. Some of the parents, especially those who already had ongoing health concerns, worried that their own health as they aged would have a major impact on their ability to provide care for their son/daughter.

The issues are health related from my point of view. Will I be able to physically care for him in the future? He is such a big lad. He is 6 feet 2. I live in a very small terraced house and really I’m thinking at some point in the future we are going to have to move to somewhere suitable if he is going to stay with us long term. I have had very little guidance about making decisions for the future. (Carer 17)

Some of the families were concerned that their child's condition would deteriorate, or that they would be unable to cope without the present level of support. Parents generally thought ahead but at times were overwhelmed by the thought of the future.

I do get concerned about getting old and him as well, people with learning disabilities are living longer and I think it is something that I am aware of, I know there is a high instance of dementia with people with Down's Syndrome which is a big problem, I think that would be awful, I worry about my capability of keeping going because how long can you care for, as you do get very tired, and I think how long am I meant to keep the momentum up, because I am aware of the fact that he needs a lot of input and we put a lot of work in with him and how long do I keep going, I feel tired after twenty years, after forty, that's the part that I worry about. (Carer 13)

I just don't want this to be life really, from cradle to grave, I would like life at the point where had she been a normal child she probably would have been living an independent life. The other kids will get to twenty -five and happy days, they will be away, might not be necessarily married, they will probably be independent, and that is what I would like, I can't see that happening. That is where I need help and guidance as to what the options are to be in 10 - 15years time down the line and if that is what it needs, help and forward planning. (Carer 16)

3.7.3 Making future plans

All of the parent/caregivers had concerns about the future for their children, yet only six (33.3%) of the 18 families had made future plans, while the majority (50%; n=9), mainly younger caregivers, had made no future plans; three of the families had started to plan for the future for when they could no longer undertake caring responsibilities. That means that a total of 14 (77.8%) of families had not made firm plans for the future (Table 16). This is similar to the figures of a previous study of older carers (aged >60 years) where 72% of the respondents had not made future care arrangements (Dillenburg & McKerr 2009a).

Table 16: Age and number of families with regard to arrangements and future planning

Arrangement	Future plans made	Starting to plan	No future plans
<60 years of age (n=14)	4	2	8
>60 years of age (n=4)	2	1	1

I would like him to stay at the level we have achieved for him as long as possible. I would like somewhere like an independent living arrangement where he could maintain that level. Of course there can be financial arrangements made but he cannot manage his own finances so ultimately he would have to be given over to state authorities. He cannot be living independently and look after himself. (Carer 8)

The main reason for not making plans is that there's nothing available for her, although they were talking about opening all new places, we were at meetings after meetings, then the recession came in. All I want is a better life for [name]; I want nice pleasant surroundings for her. I'm not asking for much, I just want a nice, homely place for her, not a hospital ward. (Carer 18)

Although some of the parent/caregivers indicated that their families had made detailed preparations, either in terms of making financial provision (including drawing up a Will) or formally drafted provision for future care of their children, the majority (57.1%, n= 8) of the families had not made future plans.

Haven't done anything formally as such, but it's an issue and it's something as he gets older will become more of an issue. You are aware of that pressure, and in a way because he is an only child it has been good that we have been able to focus on helping him achieve what he has, but you are aware that he is an only child and there aren't any siblings, typically developing siblings, who would be able to assist in his transition. (Carer 1)

For those who had not made any plans, four caregivers felt they did not have any information, or did not know where to go to find out:

I don't know who to go to, or ask about it. I suppose I could ask the social worker. I have thought about it, if something happens to me what would happen to [name], whenever I do get older. (Carer 4)

I'm scared to think about, you know, if I'm not going to be around, who's going to look after [name]? I'm not happy about it, but I try not to think about it. (Carer 19)

Many of the parents whose views are included here have watched the needs of their sons and daughters change over the years they have spent together. The following section draws together the views of parents who have recently received a diagnosis for their children, and are just beginning to think about the issues around bringing up a child with disabilities.

Section 4. Parent/caregivers: Focus group findings

Members of the parent/carer focus group were mothers of very young children (average age of children 4.3 years) diagnosed with ASD, who met regularly in a voluntary sector early intervention programme support group. As such, they were receiving at least a minimum of support. Six (66.6%) of them were not in paid employment, two were in part-time employment, and one was in full-time employment, although she expressed concerns about being able to continue after her child left pre-school.

We use a nursery, but we wonder what do we do with him after nursery? There must be childminders who won't take children with difficult behaviour, a child who's still in nappies, won't walk outside.

4.1 Access to services and support

Appropriate childcare provision outside the home was viewed as essential if they were to continue with their jobs. However, parents were concerned about the lack of awareness and training on the part of service providers and health practitioners in general. Many of them felt that their concerns were not taken seriously but rather dismissed, and the resulting lack of awareness meant that services were not tailored to the specific needs of their child.

The social workers, at the first meeting the head one asked: 'Is he autistic or is he on the spectrum?' The head social worker! They should have basic training. They're bound to come across autistic children.

I went to the GP to get [name] a pre-school injection and I asked for the flu injection while he was there because he's at a special needs school. He says: 'Why does he need to get it?' I said: 'He has a diagnosis of autism and he goes to a special needs school and there are children there with breathing difficulties. They lost a child last year to it.' Here he was (we were going out the door to get his pre-school injection): 'Autism, don't get me started, this wasn't around years ago, parents just coped with their badly behaved children.' That was a GP!

The great majority of the parents were concerned with support that addressed the behavioural issues associated with their child's diagnosis. Many of them interpreted the question regarding childcare as being directly related to practical support for them

and their children, which would have long-term benefits for everyone. As well as early intervention, parents wanted this support to be part of a wider, much more structured service, given the physical and emotional stress of dealing with both the long-term implications of the diagnosis and the day-to-day management of their children.

Early intervention is where funding needs to be put. It costs between £15-20,000 per classroom assistant, for a year, you know, if you had the early intervention put in that child may not need to go for that.

I think you really need a mentor. Of course, you want to do this for your child but sometimes you have only just been diagnosed after you get the diagnosis, a couple of weeks later you just feel absolutely broken, your energy levels go way down.

You need a care worker who will come out to you and say: 'This is what's available, I will sit with you'. Because some days you don't have the emotional reserves, and you think there must be so much more out there that I'm not tapping into, so a caseworker who could come out to you and say: 'This is what's available here are the numbers, can you phone or do you want me to phone, what else do you need, what are your needs?', not 'Here's a waiting list' and 'Maybe'.

One of the caregivers reflected on her early experiences and was not afraid to acknowledge errors or lack of awareness in the past.

We really need the early parent training. I know that for the last 9 years I've fallen into some very bad habits. I didn't know that at the time.

Apart from the lack of support, parents were also critical of the lack of information on whatever services were actually available. A number of parents felt that such information should be collated and the services sign-posted more clearly.

When you get diagnosed, you get a pack of leaflets and that is it.

I didn't hear much after 'So, he's diagnosed with autism and this is the help you get'.

4.2 Support within the extended family

Given the range of their children's challenging behaviours, family based care with other familiar adults was not always possible.

My mother and father-in-law are both in their seventies and both are hard of hearing so they can't always understand what he's saying you could drop off [name] and he would go into a tantrum, and it could go on for over an hour if the right drink wasn't given to him or they could take him to the shop and he would get out of the buggy. They would speak to someone maybe for a few seconds and look in the buggy and he's not there. He runs if he sees something. See trying to explain all that to someone?

Some parents in the focus group had more family support, but this was not always from immediate family; when families did offer to take children for a break, it was usually for short periods of time.

My sister-in-law's mother is very good, there are times she would have all five children.

Even my mum who's great and worked in special needs all her life says, 'Oh bring them over for a couple of hours' and after two hours she's going, 'Phone your mother!', because she has had enough!

One of the members of the focus group was a grandparent, and although in the main she had caring responsibilities for her granddaughter, occasionally she looked after her young grandson and could see the position from the other side.

My daughter's trick is to come round and say, 'Mammy, I forgot something in the house, I'll just drop round', and leaves [name] and then 'When I was in the house I just done this wee bit of ironing'! He only sees his daddy a couple of hours a week and his other granny is only starting to take him now and they don't understand autism. You love to see them coming but you love to see them both going home.

4.3 Services and support outside the family

Although parents in this focus group had not sought services for very long, a number were already disillusioned with the system. Even with the prospect of increased effectiveness in diagnosis through the Regional ASD Network (RASDN) initiative, parents felt there were many drawbacks.

If they are going to be diagnosing 500 kids a week, where are the services for them?

When [name] was diagnosed the paediatrician said: 'Everything's changing now.' That was October. 'It will all be much easier and you won't have to be the one pushing for things.' She sent me a letter within the week for the Education and Library Board but you have to be re-diagnosed in front of a panel.

4.3.1 Interventions following diagnosis

Parents reported that the programme they were involved with, that was offered by a voluntary agency and funded by the local Health and Social Care Trust, was the only support offered to them immediately after diagnosis. The project is an early intervention programme lasting 10 weeks and is offered to 6 children at a time, with a peer support group that continued after the intervention for the children finished. The peer support group viewed as an important factor for many of these parents.

No-one else offers us a support group with a crèche, so that's how we can make it, to come here.

Although their children were recently diagnosed, all the parents were very well informed about their options, and had considered the need for early intervention crucial for future progress. Parents all agreed that it was important to get the approach right, at the beginning. Those who had completed the programme could see measurable improvements in their child's behaviour both at home and in pre-school placements.

I went to [name of group] straightaway. My first child was too old for the [name of group] placement by the time he was diagnosed but we were offered the 6-weeks training in the evening. With my second child we were lucky to get on it, and we've just finished it. It was completely life-changing, it has just been amazing the biggest support I've ever had.

Our little one is starting [name] specialist nursery. We went before, but he couldn't. He screamed the walls down and I'd given up, he was having none of it, and then we went through the programme here and he walked through the door, no problems.

The difference between receiving general advice from professionals and early intervention was viewed as the element of practice combined with instruction.

It's that [name of group] brings you to work with your child which is the

most important thing I mean, I've read every book that I could think of, gone to the training sessions etc, but never really got it until I came here and you work with your child and you can't give up because the professionals are watching you.

In some instances, skills and attitudes acquired through the course were transferred to other situations.

We've now got it implemented in the house and my 6-year-old is doing the same kind of things, all the picture exchange, it's amazing, honestly, it's life-changing.

However, there was general agreement that they were very fortunate in securing their places. Parents were aware that as children are diagnosed more rapidly than in the past (Keenan et al. 2010), follow-up services lag behind.

Everything you hear, you know I'm teacher-trained, and it's 'early intervention, early intervention, early intervention' and then there's a year's waiting list!

You do need it. I've waited two years, with [name] who's now nine and last week we saw the clinical psychologist. We were sent to the wrong psychologist, the consultant they saw didn't write down on the psychology report that she had learning difficulties and we waited six or seven months to go to the wrong psychologist, and then another six or seven months to go to the right one. She slipped between the cracks, because the autistic tendencies didn't come out until she was older, they were hidden, hidden behind the learning difficulties.

I said ok, so what else is there for him and they said there were intervention therapists and you should get a few blocks of that. So I said 'how long is the waiting list' and the waiting list is about 8-10 months. So, he isn't going to get it pre 'pre-school'. Before pre-school you need to have a diagnosis, but you don't get a diagnosis until age three. So, the system doesn't match what is happening on the ground.

The recent rise in numbers of children with autism, and the corresponding lack of adequate services has led to a perception of a 'post-code lottery' of service availability. The area in which this group operated was seen as one of the better statutory providers; one parent, having returned to Northern Ireland because of her child's diagnosis, moved house to obtain better services.

We changed Trusts, we were living abroad, and we had to make the decision do we go back or do we stay here. So they pushed through the diagnosis early otherwise we'd have had to wait until he was three to see anybody, because

that's when their pathways start. The professionals will say it's funding driven, what is the point of telling parents your two-year-old has autism when there's no support?

In general, interventions provided by the local Health and Social Care Trust consisted of speech therapy. Some children were offered occupational therapy, but this was not intensive and generally not regular; for many children, these services were difficult to obtain, and waiting lists were a major issue.

Speech therapy comes in six-week blocks, but once it's over you're put to the back of the queue again.

It's by going to support groups that you can get ideas, but if it was a physical thing, if it was cancer you don't go into this world and say 'What the flip do I do now?' You might have to wait, it's not a perfect system but you're not completely on your own.

And the waiting lists. They used to buy in services from [name of support group] but they have their own now, it's just rubbish and there's a huge waiting list.

It was important for parents that any services they received were not 'one-off' support, but that the progress they saw with their children should be maintained, although the options were very limited. Older children who were not yet at school were seen as particularly vulnerable, falling between early intervention projects and the few projects that were designed for school children.

Between four and five there isn't anything. Up to four there's [name of support group] then no-one else takes you until after five.

For children in pre-school or primary school, speech and language therapy was seen as the main intervention, and for the majority this was delivered through the special education system. Where this was provided on a regular basis, parents found it had positive outcomes for their children, but acknowledged that parents outside the system may have difficulties accessing such support.

There's a speech and language unit [at school], he was 5 when he started, really hardly speaking, maybe three words, and after a couple of months, he hasn't stopped talking! He's in P2 and you get every detail of every day it's amazing and they have a support group up there too, every Friday you

can bring other siblings along, and they bring the child out of the classroom

My wee one has learning difficulties and he's in special education, so he's getting occupational therapy and speech therapy within the school because it's all provided but if you're not in education, it's a fight.

4.3.2 Accessing pre-school services

The major obstacle to finding suitable childcare was their child's behaviour, mainly in terms of communication, rigidity of behaviour patterns, and toilet training. Parents' main worry was how child behaviour problems could be accommodated within services that were usually designed for typically developing children. They also worried about what would happen after pre-school.

We use a nursery, but we wonder what do we do with him after nursery? There must be childminders who take children with difficult behaviour, a child who's still in nappies, won't walk outside.

For parents, there were real obstacles around the admissions procedure for children who were not toilet trained. Many nurseries and crèches refuse places to children who are still in nappies. Parents felt that they would benefit from the assistance of staff in establishing toileting routines.

My child is in mainstream nursery and the idea is you can't come unless he's potty trained. The social worker is putting pressure on [name] saying: 'You will have him potty trained, he needs routine. I don't understand this.' I said: 'You don't understand autism.'

From the school perspective you can understand if you have to take the teacher and the classroom assistant to go out of the room for health and safety or for legal issues, who else do you leave in the room to look after the other 26 kids? So you can understand.

Our crèche is so good, it's so laidback, they don't say this is the age he should be toilet trained or he won't go on to the next room or whatever, so they're very good, but other crèches are so strict I would have got the feeling they wouldn't want him there because of it.

4.3.3 Services provided through schools

Parents reported positive experiences with special schools. In particular, they stressed the value of teacher experience and awareness of issues around ASD, and also good communication skills.

You get a book home every day if your child has bad speech, and a lot of them have bad speech, and they write down what's happened, maybe they've fallen and you write back to the teachers.

[Name's] school is a wonderful school. We dread the annual review in case they say [name] doesn't need us any more. I think [name] would chain herself to the front door!

However, parents also reported obstacles to accessing suitable provision, with delayed diagnosis a major factor.

If you get the diagnosis after the deadline [for admission applications for P1 special education], then you can't.

With my youngest, he was two and four months. I refused to leave until they gave me a diagnosis, they said 'we're not going to give you a diagnosis today, I don't think you're ready for it, we'll have another little chat', and I said that I had heard off the record that they do this, and I had another son with it' and I said 'well I'm not leaving'.

I feel if I had got this service from my first child, I wouldn't have had to take it up the second time round as well, the training the first time was a different type of training whereas this training is so much more and had we had that first time round we could have implemented it all ourselves.

4.3.4 Short breaks and respite services

None of the parents in the focus group used statutory respite or short break services. This may be because their children were still very young, although some agencies offer short breaks to children from birth. Lack of uptake of respite may result from their perceptions of their own role as parents rather than 'caregivers'; they were surprised that they were regarded as 'caregivers' and saw their role simply as parents of children who needed extra support. Having said this, concerns were expressed about the suitability of respite, in particular with regard to the continuity of care provided and the worry about the safety of their very young child.

I don't know if I would trust them I've heard so many times: 'If you apply for it, you get one person one week and a different person for the next week', which for autism doesn't work, and you know it took three months to get [name] in this door! So, to get someone to do respite?

If you get an hour break you have to spend an hour and a half explaining... [General laughter]... about that stuff and then you can't relax unless it's someone you really trust...

Because they can't speak so well you're reluctant, if anything goes wrong, they can't tell you...

Where other specialist or tailored provision existed, such as a crèche or home sitting service, it provided a short but valuable breathing space for parents.

My wee boy goes to [name of service], a wee crèche and they take a play and development class from 9 until 12 on a Thursday. There would be six children and there would be six workers so it's one-on-one. That gives me two hours. I can do my food shopping. They're starting another one which has speech therapy so that will give me another hour and a half so I can go home and just tidy the place up. That's three and a half hours a week that I have to myself.

I have a wee girl who comes out, just whenever I need her I belong to a support group and they provide respite. It's only an hour maybe every now and again when you need it but I don't feel comfortable leaving her on her own but she's in the house and then I can go and do my ironing in the kitchen and I know he won't run in and maybe run into the iron- she's keeping his attention by playing with him I can relax a wee bit and maybe go and watch TV

4.4 Planning for the future

While acknowledging real concerns for the future, parents in the focus group generally had a positive approach. For them, planning for the future involved getting it right at the start, and making changes now, equipping themselves and their children with skills through behavioural interventions that would avoid many of the future problems that older parent/caregivers had experienced.

The more work you put in now when they're younger, it's going to make it easier but you're always going to need that extra. But you worry. I mean I'm a single parent, I don't have that much family other than my mum and dad, so I'm very 'What if something happens to me, and my mum, what happens to my child?' It is something I worry about for the future. You can't dwell on it because it just makes you go mad but what is there out there? It would be nice if he needs it, things are out there.

This programme shows you how to work with those behaviours, about warning signs. My six-year-old, his behaviour is worse than my three-year-old because he didn't have that, so that's where I see my future. It will be controlled with visuals, controlled with diaries or whatever, you know

However, in practical terms, these parents planned their lives from day to day, month to month, rather than making longer-term decisions. Organising the demands around immediate needs of their children was their primary concern.

It takes so much energy to fight for that, you can't... I can't even think of next year. I'm thinking of nursery, and getting a place before nursery.

They also experienced some public attitudes as hurtful and disappointing, and they felt that other people should be made aware of ASD.

The older relatives tell you: 'He needs a good slap on the backside.'

Here he was, we were going out the door to get his pre-school injection, 'Autism, don't get me started, this wasn't around years ago, parents just coped with their badly behaved children' and that was a GP...

They'll say, 'Oh, he's quite high functioning' but forget what everybody says, it's going to be difficult regardless. You will get through it, if the support's great but you know, I remember my family saying: 'Och, there's nothing wrong with him'.

This section has documented the opinions and the very specific needs of families with pre-school children in particular; in the following section, we examine the views and experiences of young adults with disabilities who are moving towards leading more independent lives.

Section 5. Young adult service users: Focus group findings

The participants in this focus group were young adults with learning disabilities, including Down's syndrome. Notwithstanding their age (between 19 and 29 years; average age 23.5 years) all of these young adults lived at home with their parents. Four also had siblings living at home, and one individual lived with her mother and grandmother. In addition, they were all involved in services outside the home, such as the support group run by a voluntary organisation and work and leisure activities.

5.1 Home and family life

In talking about how they spent time at home, most said they helped with household tasks, and some considered this both a very positive responsibility and an accomplishment they could take pleasure in.

I would call myself the golden girl because I'm always helping out my mum because I'm always ironing and I'm always doing house chores. 'Cos ironing is a job that I'm really good at, I enjoy it, and I help my mummy.

However, helping out around the house was not a priority for all:

I help out my mum and my dad sometimes, helping to make the dinner or sometimes clean the house- only sometimes but I don't try a lot, but only sometimes and I play the guitar, and practice a lot.

All of the participants had a very active interest in new technologies; all had access to a computer at home and some had personal cable or satellite televisions in their rooms. When asked how they spent the time when they weren't helping out, the most frequent responses related to social network sites and television. However, they were also very much engaged with sporting and social activities.

I help my mummy. I'd be more willing to do it than my brother anyway, so I would, and I go on the Internet.

I go out line dancing three nights a week, sometimes there's a competition.

I'm not usually in the house at night 'cos I like to go out; clubs like Drama, gymnastics and tag rugby.

Living at home was seen as a positive experience for most, and they expressed that they had acquired a sense of independence and confidence about their skills.

Having independence, and be able to have the ability to look after yourself and to know that you have the responsibilities of making sure that the house is tidy...

They also valued having their own space within the home, and looking after their room was seen as a responsibility (with certain benefits):

It means you can get away from your parents!! [General laughter]

There was only one negative response to living at home, where the individual felt that the other adults were noisy, especially with appliances like the television and radio, and this was an irritation:

The problem in our house is that ours is a bungalow and our walls are a bit like paper and I can hear them ...

5.2 Services and support outside the family

The focus group members were all very active socially and were involved in educational, employment and leisure activities that took them outside the home on a regular basis.

5.2.1 Short breaks and holidays

All group members lived at home and they nearly all enjoyed holidays or short breaks throughout the year; these were not just local, but involved holidays in England and abroad. For many, these were not ‘respite’ in the strictest sense, they were family occasions.

I get away to Spain with my mum and dad, in an apartment in Spain.

I go with my friend. We went for a trip to Australia! [Friend's name]'s mum and dad and family come too.

Some of these breaks were linked to other leisure activities such as sports or social groups, and some involved a degree of commitment to community involvement and social awareness on the part of participants (as well as a sense of adventure).

Well, I'm also a member of the [name] Association for people with learning disabilities and they do residential holidays. You get away to, Spain, or sometimes to the [name] Centre but that's only for the younger group but the older ones go to Spain.

You know there's a group for the Special Olympics which I'm in. I've been selected to go to Greece for the World Games and I'm going over in June to Turkey. 'Cos the games start on the 25th June so I'm going a few days early to acclimatise, to get used to the weather.

Having a disability was not seen as a barrier for the young people in the group; they were very involved in local politics, in lobbying for disability rights and (as with many other people of their age) interested in becoming involved in projects that improved the lives of people in developing countries:

Have you heard of a thing, [name of charity]. Well they went through the Association and they're taking a group away over to, I think it's South Africa or something like that, to build houses for people who are in need of care.

Respite stays or short breaks through statutory agencies were a less common form of holiday for the group, and only one member actually reported going to an organised residential setting. One individual had not been away, either as part of a group or in the family.

My respite is in [name of town] gives my mum a break from me. Sometimes I go for a week or so, it all depends.

Some people, like me, haven't been away from home.

5.2.2 Clubs and other social organisations

Parents who participated in individual interviews for this study reported a lack of social networking for their children with disabilities, and this was seen as a distinctive disadvantage for sons and daughters (of all ages) and in terms of allowing parents a break in caring responsibilities. The focus group, however, reported many opportunities linked to sports and social activities, and this had been actively sought out and supported by their parents, often when they were younger.

Well at first, ages ago when I was younger, the only thing I would do in the evenings was watch TV and do knitting, whereas now I'm involved in many clubs in the evening because of my mum and dad have been making friends with other parents whose children have disabilities, who know a whole lot of clubs that would let us get involved so that's how they got me into the clubs and so on.

I go out too. Mum's never seen me all weekend! My mum took me down for my snooker tournament, in my snooker team every Saturday. My Mum leaves me down at the snooker hall, she leaves me there and Mum goes back home again. I look after myself. My Mum doesn't stay, all my friends in my snooker team look after me, everybody in my snooker team knows me.

In one instance, a group member had helped found a social club that had expanded to include younger members, and others had been creative within existing groups, running special events to highlight sporting activities and raise funds.

I go to a youth club down at home. It's for disabled, I actually helped to form it. It's a youth club. The wee-er children have a youth club too and a time there at Christmas both groups met and it was nice to see the wee kids.

I go to drama on Mondays, at night, and we're putting a show on. Anyway [name] is going to Athens and we're doing this thing, it's like a charity thing, for the Special Olympics.

It's to raise funds for us to go over, so I, myself and my friend have been chosen so we have to go round and put on a performance to show people what sort of things we are going to be doing over there, because it's about balance, and getting people to come in to watch what things are going to be on so it can help raise some funds to help us go.

However, since many of the group were in their mid-twenties, they felt that the clubs and activities were becoming less age-appropriate.

The thing about youth clubs, there's not enough for older people. Most of the clubs are up to a certain age.

There isn't anywhere for older people to go to. It usually ends at, like, 25.

When asked what kinds of activities they would prefer for over 25s, there was a general consensus that activities such as bowling, snooker, or trips to the cinema, which involved groups of friends, would be more appropriate for their age group.

Some of the participants acknowledged that their parents had a major say in organising these activities; for some, it was totally up to parents, while for others, it was a process of negotiation. A growing awareness of a need for more independence (as with looking after the household tasks) was evidenced by many of the group. For others, they had already taken the first steps towards social independence in a new relationship.

Sometimes I go out to see my friends because I have to do things outside, that I don't do in the house. It means you can do things without your Mum and Dad, you have to do things by yourself.

[Name] and I are a couple, we go out on dates.

Access to social groups however was still dependent on parental support with transport; only one group member used public transport (the bus) occasionally for evening activities, and one other group member drove his own car.

My Mum and my Dad both drive a car; my Dad drives a car and a motorbike to my snooker team.

Well, my two brothers drive, my parents drive and my sister drives. I'm the only one in the family who's not driving- my younger brother just passed the test.

5.2.3 Work, college and day-centres

All of the group members had occupations that took them out of the house on a regular basis during the day, and this varied from five days a week to three days a week; 77% (n=7) were employed and/or in college and two individuals attended day centres.

I work and go to college. I work in the office of a school.

I'm at the day centre too, but I'm in a different day centre to the one he's in. I do three days a week, I mean catering two days a week I'm in the kitchen and we cook break and lunch for everybody else and then on a Friday I'm in the computers.

The college placements offered a range of qualifications, and most of the group were ambitious in terms of improving their educational experiences through

obtaining national qualifications, such as NVQs, although some were sceptical of the quality of other awards.

When I'm in college I'd like to improve my skills so it means you can help out at home and cook dinner for your family I'd like to improve my skills. I'm leaving school and in September I'm going to [name], the same college as [name], on a course.

I'd like to explain what [name] means, it's all to do with independent living and all the skills you need to know about money management and learning how to keep your house tidy, and you learn about cleaning products and how to clean around the house, independent living, things that you need to learn about the house on Monday afternoons it's just all about that sort of thing.

I've got NVQ level 1 and level 2 in Business Administration I just passed them all. Now I'm working, and I am finished my exams.

It's sort of like NVQ, but it's like an easier version, it's more ...I just did my Health and Safety for the kitchen ...Well I achieved a pass, but it's not really hard to do.

Those who worked most of the week had jobs in retail, either in major multinational stores, or local shops, which were limited in terms of time but which were flexible enough to allow some group members to carry out two part-time jobs.

My dad or sometimes my mum would maybe make my breakfast and I go to work around half twelve in the café. I work in a different café on a Wednesday.

When asked about acquiring new skills that would improve their opportunities, there was consensus around wanting to learn to drive a car, a skill that would offered independence, both in terms of social activities and work. The drawbacks, i.e., the cost of running a car, and the work involved in passing the theory test, were also considered, although only a few of the participants seemed discouraged by these aspects.

I put in our suggestion box that we should have a course for anyone who wants to learn how to drive- I'm still waiting on a 'yes', 'no' or 'bugger off'!

I know, I'd like to drive a car but my head's not focussed sometimes. I'd learn lots of theory and there's all the money it's dear.

5.3 Young adults planning for the future

All members of the focus group lived in the family home with their parents. Only one young person was on a housing list, but the consensus was that independent living was something to aim for. The reasons for living at home were fairly evenly divided between a feeling that they themselves needed more time to get ready for the move or that they were needed at home, and perceived unwillingness on the part of their parents to let them be more independent.

No, I'd like to go, but my problem is that my mum isn't ready to let me leave.

I don't want to leave the house, I know it's to be decided, but there's things you have to do around the house.

There's something about she wants me to be independent and stuff, but how can I be independent if she won't let me go into independent living?

It's nice to have someone worried about you but sometimes you need to say, 'Look, let me be independent.' But it's good for someone to be worrying.

However independent these young adults hope to become, the majority will almost certainly want to access services to support them in their future lives. In the next section of this report, service provision will be examined from the perspective of the providers, from both the statutory and the voluntary sector.

Section 6. Service providers: Individual interview findings

6.1 Service profiles

Table 17 shows the profiles of service providers who took part in individual interviews. While these service providers represented statutory (n=4) and voluntary (n=9) service provision across all age ranges and disabilities, they did not provide a fully comprehensive audit of services, and as such, only snapshots of the realities of service provision were given.

Table 17: Service providers: Individual interviews

Provider	Service	Age (service user)	Disability category	Number using service
Statutory (Stat. 1) Sen. social worker ret.	Mental health support	3-18 years	a - f	Caseload 100 Service 1000+
Statutory (Stat. 2) Social worker	Short breaks	0-18 years	a, b-e (dual diagnosis)	Caseload 30 Service 450
Statutory (Stat. 3) Manager	Adult day-care	18 ⁺ years	a-f	100 service users
Statutory (Stat. 4) Social worker	Short breaks	0-18 years	a-e	Short breaks: 108 Social groups: 11
Voluntary (Vol. 1) Information officer	Advisory	10-90 ⁺ years	a-e	1500 service users
Voluntary (Vol. 2) Behaviour analyst	Parent training	2-33 ⁺ years	a, c, d	Caseload 54 240 access services
Voluntary (Vol. 3) Manager	Short breaks and residential	7-18 years	a-e	4 full-time residents 11 short breaks
Voluntary (Vol. 4) Childminder	Childcare	6 mths- 12 yrs	a-d	4 children (1 with disability)
Voluntary (Vol. 5) Project manager	Support group	8-18 years	a-e	145 service users
Voluntary (Vol. 6) Deputy manager	Support and Short breaks	0-65 years	b,+a, d, c, e	170 children 30 adults
Voluntary (Vol. 7) Project worker	Mental health support	18 ⁺ years	e	14 service users
Voluntary (Vol. 8) Director	Sensory disability	0-18 years	d +a, b, c and e	700 families
Voluntary (Vol. 9) Operations manager	Family support	8-18 years	a (dual diagnosis)	150 families

*a. Learning disabilities b. physical disabilities c. behavioural issues
d. sensory impairments e. mental health issues f. other disability*

6.1.1 Funding of services

All four statutory providers and one voluntary provider were fully funded by HSC Trusts; one voluntary provider relied on another form of direct support (through the *Supporting People* programme⁷), one was supported by a grant from a larger charity and one relied on direct fundraising. Parents met the costs of childcare with the registered childminder and some of them claimed the fees back, although this was not always straightforward.

Parents pay, and sometimes parents get paid by Tax Credit vouchers, and they would help with the payments and most of our parents actually use the voucher method, from the Employers for Childcare. Years ago I used to get it when I first started up, it was paper method, where the parents used to come along with the voucher and you signed it and sent it off and then it was in your bank, that was fine but with this other method it depends on whether the parent does it in time for it to be put into your account, but the parents can't do it until they get paid. (Vol. 4)

Some of the services delivered by voluntary agencies were part-funded by local HSC Trusts, (55.6%; n=5) however, the current emphasis on austerity and budget restrictions means that such collaborations are likely to become more common in future.

6.1.2 Access to services

The majority of providers (77%, n=10) accepted referrals from more than one source, and the profile for criteria in accessing services was similar in statutory and voluntary sector providers. Although the opportunities for self/parental referral were higher in the voluntary sector (66.7% n=6), compared to the statutory sector (50%, n= 2), the sample was small and no breakdown of proportions was sought from participants. Overall, most referrals came from a social worker (69%; n=9), self or a relative (61.5%; n=8), medical professional (n=5), or other professional (n=4). Two statutory providers (both involved with respite/short breaks services) only accepted referrals from a social worker and parent/carers who do not have a social worker, whether by choice, breakdown of

⁷ 'Supporting People is the government programme for funding, planning and monitoring housing related support services. Its aim is to improve the quality and effectiveness of the support services at a local level'. See http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/SupportedHousingSchemes/DG_4000297).

communication, or because they do not qualify for access to a social work team, would automatically be excluded from this service (see Section 3.4.2).

The families need to be known to the children's disability team, so a referral through to the children's disability team if 'short breaks' is what they require. An assessment would be brought to the children's disability team resource panel and then the most appropriate form of short breaks would be decided, and then they come to me. (Stat. 4)

Mainstream childcare providers such as childminders usually took self-referrals but were more limited as to the level of disabilities they could provide for.

That is a big thing for me, I am very strict when it comes to behaviour issues in the home, because I have my children and I have to consider them first. So depending on where the behavioural issue comes, I always give everybody a chance, like a settling in period, because I have had children in the past where they have had really bad behavioural issues. They have had their time here and now they have moved on. (Vol. 4)

6.1.3 Staff training

The majority of providers (85%, n=11) came from a professional background such as social work, management, or teaching; 61.5% (n=8) had third-level qualifications, and two had an additional qualification at Master's level. Twelve undertook on-going training based around their work.

They offer across the board training for everything, child protection, behaviour, business studies, or child's play. Before we become registered we have to do a certain amount, we have to do the child protection and an eight-week course, it's very basic it just touches on disability training. I go to them all, I do all the training as the training needs constantly updated. (Vol. 4)

6.2 Services provided

Although HSC Trusts and voluntary groups can also provide support for activities and interventions at home, the majority of those interviewed offered services outside the family home.

6.2.1 Services outside the family home

Two statutory agencies provided respite or short breaks primarily for children with a learning disability, up to 18 years of age, co-ordinating with specially trained caregivers, a process that is both lengthy and cost-intensive:

I would work with children with a severe learning disability so the service we would provide would be social work support, which is very much an access to services. My own role would be to co-ordinate the [name] short breaks scheme, which provides day-care or overnight stays. At present we have about 30 children in my scheme who avail of it and I would also be responsible for the recruitment and assessment of carers. They are equivalent to fostering regulations. In short breaks the maximum number of nights you would get is 90, the carers receive a fee and boarding out allowances. (Stat.2)

Short break services were also provide by a number of the voluntary agencies in a variety of different formats.

Our current service is to provide both the permanent carer with respite care and permanent care up to the age of 18 years, for children with a diagnosis of severe learning difficulties and challenging behaviours, and similarly for respite for children with the same diagnoses again up to the age of 18 years. We have no lower age range, but the lowest age we have worked with was a child who was 7 or 8 years old. (Vol. 3)

Short breaks were mainly arranged in another caregiver's home or in residential settings, but also included a number of related projects that were developed reflecting the specific interests of team-members.

We have a range of in-house activities, such as art workshops, social groups, and puberty groups. We had a recent student here [on placement] and he ran a football group. The other big part of the team would be the paediatric end. We would have a lot of young people with autism. We have three or four social workers who are involved with parents, to meet together and discuss access to services. (Stat. 2)

Services within the voluntary sector included leisure, social, and community activities, support for siblings, parents, and carers, and community development work.

We have our [name] Service which is a short break service for families of children with disabilities for children from 5 up to 19 providing social activities with a view to breaking down barriers in their local area, looking at disability awareness training and getting the children into some kind of mainstream provision in their area whether it be a group or youth club looking at getting them into some kind of inclusive activity. (Vol. 6)

Where service users' needs fell outside the criteria of a service provider, statutory service providers referred families to other services, either within their own Trust or to voluntary agencies, although at times there were restrictions on access to services depending on the child's needs.

I would pick up the phone and ring people, you know, if I felt somebody would benefit from a service- for example the services for children with disabilities in the [name of HSC Trust area] the criteria changed I think about two years ago which made it extremely difficult for people with either mixed syndromes or... like for example they had to attend a special, a nominated special school, so really only people towards the more severe end of learning disabilities would have got in, despite every other problem there may be, and there was no give on that whatever. (Stat. 1)

Frequency of service delivery ranged from daily, e.g., childminding, adult day-care, and children's residential services, to once-off consultations and short-term placements, e.g., mental health and respite/short breaks services. Some providers expressed concerns that the service was limited by capacity.

It depends on need and on carer availability. Children could go potentially once a fortnight for four hours or twice a week for four hours or they could have a single overnight or a full weekend a month. That is probably the variety that we have. The overnight probably fortnightly would be the maximum, or once a month is the average. A child might go for three daycares and one overnight a month, that's how it used to be. We tend to see now coming from the resource panel that the service is fortnightly rather than weekly. Again it's down to budgets. (Stat. 4)

6.2.2 Children's and adult services

Within statutory services, there is a very sharp division between children and adult services. Children's services generally applied until the 18th birthday (21 for some young people with disabilities).

Children who maybe wouldn't have survived several years ago are surviving, and there's always been a bottleneck, more children moving into adult services than they have the supply for, but we're now getting so many, and it used to be that we would provide a cradle to grave service but now we 'd be writing to families and saying 'If you no longer require a service, let us know and we'll be available if you need to re-refer.' But for some families, we really aren't seeing them, and looking to see how to meet the needs of those that do require our services, and our children's needs have become so much greater. (Stat. 2)

The separation between children and adult services was mirrored in the majority of voluntary groups; four participants offered services for children, and one offered

services for adults. However, one voluntary service offered general advice and had no age-dependant cut-off point. Lack of continuity was a concern for a number of parents and the demand for adult services was a concern for some providers.

We have four permanent residents, three 13-year-old boys and one girl who is turning 18 this month. She is going to a new unit from another housing provider. Again, it's a purpose built environment, so she will transition up there within the next few months. This frees up a permanent bed, very often for the permanent children it's delayed discharge from hospital that we haven't moved into a permanent bed, so it's children who have been in [name of hospital] for a period of time and there has been nowhere for them to transition to, for a lack of bed space, so the current waiting list would be delayed discharge from hospital for that permanent bed. (Vol. 3)

The participants who represented short breaks providers both stressed the importance of training for their caregivers and the confidence this inspired in parents. However, regardless of the relationship between the family and the short break caregiver, this terminated once the child reached 18 years, unless the respite caregiver themselves moved to adult services.

Once the placement is made people become very content. Our service could last right through to adulthood. We lose carers when the young person turns 18 because maybe then the carer transfers to adult services, but it is wonderful for the family. (Stat 4)

Some voluntary groups offered services tailored specifically to different ages, which meant that there was a continuity of involvement for families. Of course, with regard to planning and delivery these kinds of services needed additional resources. This was facilitated at times because funding mechanisms in the voluntary service were more flexible and reactive than funding for statutory providers.

Our Transition Service works with the transition from school, working with the young person in their final year at school either 5th year or lower/upper 6, and then supporting them in the move to their next provision, making sure the support is in place and then a follow up/tracking year monitoring their progress to make sure that things are going well and if there are any problems you are there to step in straight away to support them or identify any provision, if its not working. (Vol. 6)

Specific programmes were tailored to specific areas in response to a growing need within a relatively short period of time, by targeting funding applications, with the obvious drawback of maintaining the stability of services and retaining skilled staff.

6.3 Service evaluation

All service providers mentioned that parent/caregivers generally were satisfied with the services they received, only a few mentioned critiques from service users (n=3).

We do ask parents to contribute to [respite] carer's⁸ reviews so that each time the carer has a formal review there is a contribution from the parent. They feel that their child is part of another family and they feel very comfortable with that. Parents get to know the [respite] carers and they do feel it's another person they can talk to. (Stat. 4)

The parent has said to me, that she would be unable to do this without me, and it's lovely and it's really nice for me at the end of the day as it is satisfying for me to know that someone needs you and you can do it for them to help them and you are still making a living. (Vol. 4)

Those who are receiving services are very happy, those who have difficulty accessing services aren't so happy. (Stat. 2)

I think for the vast majority of carers they perceive it as a very useful and valuable service. One of the issues we have is that carers often come to us at crisis point and they could have used us years ago, and hopefully we would have averted the crisis to some extent. I think people can be very angry that they didn't know the service was available to them for years, unfortunately we don't have a budget to do major publicity campaigns and things like that. So a lot of it is word of mouth and we try to get materials out there. I do hear all the time 'I wish I'd heard about you 5 years ago, 10 years ago'. (Vol. 1)

Seven service providers mentioned that parent/caregivers initially were uncertain or anxious but that through assessment of individual needs appropriate provision of services could be negotiated.

In most cases they perceive it as very important as a lot of them work and without day-care it would put them in an impossible situation. And as carers get older they rely on the service more and more. We do things in here such as personal care like bathing and showering which helps out quite a lot of carers. They really do need what we offer and a lot of what we offer is down to carers making the needs known as well. (Stat. 3)

All of the service providers reported that there was process for review or feedback from services users, in six-monthly (n=6), annual (n=4), or other regular intervals (n=2), or less regularly (n=2), and less formal (n=3). Four providers had carried out independent surveys and/or were subject to formal inspections.

⁸ 'Carer' in this context is the term used for someone who is employed in a caring capacity

After every activity they fill in feedback forms. The nicest things are the text messages like “thanks for a great day” that’s the nicest way, but we have feedback forms, we have a feeling book as well that they fill out. (Vol. 5)

We have a six-month review and also because of our magazine I would ask parents maybe to write an article for us, and they would, and the fact that a lot of our parents are now actively going out and doing fund-raising for us, so that tells you that parents are willing to help us; they want the service to be there for them. (Vol. 2)

One provider working with young people used modern technology quite extensively, allowing a very flexible system for maintaining contact (and gathering feedback) among service users:

It’s sort of like a big part of their life, we have Face Book, we have our own website and should be updated at the minute as it’s not great. We have Face Book so they know what happening all the time, which means they can go on and check out what’s happening and stuff like that. But also I would get a lot of text messages and phone calls, so it is a big part of their lives.

Service providers reported that the feedback they received identified listening and communication skills, emotional support, practical support, such as respite care and new friendships to be one of the most beneficial aspects of their service.

It gives them a break first and foremost, time to recharge their batteries. For some families it’s the only thing that keeps them going. It prevents family breakdown. It allows time for parents to spend with other children, time for themselves, time as a couple. It’s something for them to look forward to. (Stat. 4)

Security and confidence about the quality of the service was viewed as key factor for making a service acceptable to service users and caregivers.

A lot of the parents initially are quite anxious, who maybe haven’t had a service in the past, they are coping with children with a variety of difficulties such as sleep disturbance, self injurious behaviour and psychical aggression, and very often parents will worry sharing that with other workers as well as they deal with at home, so the initial concept ...when we get a new referral first of all there is a lot of work to be done in reassuring parents about the service we provide and the nature of the service. Once they have used the service for a period of time, most of our parents would be very complimentary when ever they meet with our external managers and sources... once they get that reassurance ...the child likes coming to the unit and spending time with the other children and integrating with staff and doing a range of activities, so they are very positive about the service, it takes a period of time to build that up, but they end up being positive about the service (Vol.3)

6.3.1 Improving the services: provider's perspectives

The majority of providers (92%, n= 11) said that their services could be improved, with more resources, funding arrangements and/or staff as their main priority:

We could always do with more staff. We are actually going to have our staff cut under the new spending proposals. So instead of getting more staff we are actually going to lose staff, which is a great worry to me. (Stat. 3)

I would love to see the charity being funded by the statutory bodies, so that if you get a diagnosis of autism, you automatically get a referral to a properly qualified Behaviour Analyst and not just someone who has had some experience in 'behaviour'. (Vol. 2)

One of the big things now, is we are legally obliged to undertake a Carer's Assessment, and then when it is completed, and you've put the parent through a lot of pain and then you say 'I'm sorry but we don't have a service to offer you.' (Stat. 2)

However, some providers qualified that funding alone was not the only issue they considered essential to developing and improving services. One provider felt that it was important to have more input into policy development.

I think it could be improved if people gave it more credit. It's an extremely cost effective service provided by a small number of staff and happens because we have [respite] carers dedicated to what they do. I think that while people pay lip service to what we offer, I think when push comes to shove it's the Cinderella service because it is run by a small team. (Stat. 4)

I know a lot of childminders who wouldn't [take on children with disabilities], because they are only allowed six children at one time [children with disability take up more time than one typically developing child], and they couldn't earn the same money. (Vol. 4)

Some of the service providers had suggestions related to practical improvements that would increase the effectiveness of an existing service, such as transitions, training and respite/short breaks, indicating that they are listening carefully to their service users:

We regularly use person-centred tools and approaches to review and develop our services in partnership with children/young people and parents/carers. This work happens both at a Service level e.g., reviewing and developing activities for children and an organisational level e.g. at Corporate Planning

Events, young people and families are always actively involved and fully participative. (Vol. 9)

The main thing parents are saying is not the service itself, but the move on. They would comment that the adult services should be something similar. For example, a young man; we took a long period of time transitioning him, but the only unit we could move him to was one of our own units in [name of town] so he had to move some 75 miles. (Vol. 3)

Parents are saying, 'If we could get more hours and more intensive support, look what we could achieve'. When you hear about the models that are going on in America, that's what parents are looking for here. You know, if we had all that going on, look how many kids would be going out and not in 20 years time being in care homes or living at home because they don't have the skills to go out and do things by themselves. (Vol. 2)

One of the big things now, is we are legally obliged to undertake a Carer's Assessment, and then when it is completed, and you've put the parent through a lot of pain and then you say 'I'm sorry but we don't have a service to offer you.' (Stat. 2)

In England they have contract carers who specifically care for children who have challenging behaviours. It requires a fair amount of money, because you are talking about maybe having to pay these people 18k per year minimum to recruit the right kind of people - maybe someone who has been a classroom assistant that would be prepared to give up their employment and work from home. You would have to pay them their allowances on top of that and adapt their home. A lot of input, but works tremendously well in England and they have reduced their waiting lists greatly. You recruit one person and all of a sudden you have 5 people off your waiting list. (Stat. 4)

Two providers noted that directing resources into developing life skills was more effective than providing material support.

She had all the sensory things, a special bed and jiggly toys and yet ...he was 7 or 8 and he was still in nappies and I got them to do a programme...she did that consistently and he became toilet trained... he still has the odd accident but he's washing his hands now, so she was delighted. I would have to say the family had put a lot of money in, and so had Social Services to be honest, but they hadn't looked at what she needed the most. (Stat.1)

One voluntary sector professional described how achievements in one area can transform how parents deal with other issues around disability.

Initially when they get the diagnosis there's a big... 'My child will never be able to do x, y and z' and when you go in and you put a small programme into

place such as toilet training...one parent was told by her GP that her daughter would never be toilet trained, I put an intervention into place and I went back 6 weeks later and the 4 year-old was independently toileting. Do you know, that parent was happy enough with that, that was all she wanted, whereas some parents will say ‘I’ve got that, now I want to move on to this’ and they keep moving the goal posts because they can see the difference...(Vol.2)

Having heard the views of parent/carers, service users and service providers, the following section, in which parent/carers make recommendations based on their own experiences, will conclude the data analysis section of this report.

Section 7: Recommendations from parent/caregivers

Parent/caregivers were asked to make recommendations, based on their own experiences of disability issues, for other parents, for service providers and for policy makers.

7.1 Recommendations to other parent/caregivers

Parents were asked to consider what advice would be useful for other parents who were caring for sons and daughters with disabilities.

7.1.2 Peer support

Finding dependable peer support was thought to be one of the most important factors in alleviating stress in the family home.

The best resource is talking to other parents and their experiences, and sharing your own experiences and try and take as much help as offered to you. I know a lot of people can be a bit embarrassed about accepting benefits but they're entitled to you to take, and at the end of the day, it's for your children and helps you get things that they need as well. (Carer 14)

Well I am a social being, and I just think to try as many groups as you can, it might not be for you but at least show your face, have a chat, find out what is available, get a phone number and dip in and out...(Carer 16)

7.1.3 Determination, knowledge, and getting things right from the start

Being determined and persistent about the right services and the right information were viewed as empowering. At the same time, being proactive rather than reactive was viewed as crucial to achieve best life chances for son/daughters.

You need to be bloody-minded about things, you need to keep picking away. Don't take the first or second or third response as gospel, you need to apply the donkeywork yourself, and you find out partially by accident and partially by word of mouth. You just need to try and absorb yourself as much as you can from as many different sources as possible. If you get enough information, then you feel qualified to make some sort of reasonably intelligent decision about things. (Carer 2)

Hold your ground because the chances are you will probably be right anyway and try and find out. If you have the educational background and the drive and the determination everything is possible, but some other people just accept what they are given and never question it. (Carer 16)

Don't be afraid to ask, and if you are told there is nothing available ask again and keep asking until you get to someone who says 'Yes, we can help'. (Carer 15)

Early intervention and early planning was seen as vital step to get good outcomes for sons/daughters as they grow older themselves. In particular the importance of early behavioural interventions that build life skills was singled out as important.

Think of it as a lifetime job when the foundation can be given in the early years for both your child and yourself. (Carer 8)

If you deal with issues at the very start when the child is born, it cuts down on the anger and the resentment, and everything later on in life. I think parents need somebody there at the beginning, who's a strong support and for the parents also to understand that there are up and downs it is like a roller coaster, there's days its great and other days you just can't cope anymore and for parents to understand that, and it is a grieving process at the start as you do grieve for the child you thought you were going to have. (Carer 13)

The practical advice parent/caregivers of young children had for other parents reflected their experiences at the beginning of the life-course, and focussed on educational provision.

You've got to get it out of your head the difference between special needs school and an ordinary school. It is the school that's best for your child, everybody gets hung up, 'Oh he goes to a special school'. (Focus group)

The school that is best for the child; that meets the child's needs. (Focus group)

7.1.4 Valuing family life

An important piece of advice was related to getting on with life and the enjoyment of the son/daughter as a valued family member.

Don't bury your head in the sand about it all, and just accept whatever level of learning your child is at. (Carer 6)

You think it is the end of the world now, but as time goes on you will look back and say that this is an absolute blessing here. Initially sometimes it like a building falling on top of you, and it does, and I can understand that, as when it happened to us I thought it was the end of the world. At the end of the day it is a blessing, I would say not to be concerned and get on with life. (Carers 11)

It's a major grieving process, and once you come to get through that grieving process, you realise the value of the person you have, and as a person it's fantastic to understand that value because the things I have done and the places I have been are because of him, I would have never been with another child, and that is the positive side of having a person in your life with learning disabilities. He is so uninhibited and just fantastic and spontaneous that sort of stuff, and that's the part I just think about him. (Carer 13)

7.1.5 Good relationships with professionals

Parent/caregivers thought that other parents and professionals in education, health, and social care should ensure that they had a good relationship. In particular, a good two-way process of communication and exchange of information was viewed as crucial.

For schools and for other service providers try and make sure that information is easily available. I think nowadays in the Internet age it's easier to get information- and certainly with e-mails it doesn't cost them anything to e-mail or very little, to keep people informed and to send out a PDF document on 'What we can give you.' (Carer 1)

For instance when [name] is using words at school, tell us what the words are so we can use them at home, you know, communicate! Apparently [name] is very well behaved in school- a different child. I try in the home, but I am probably not doing it right, the way they do it in school so she wouldn't do it for me the way she does it in school. Tell me what she does, and show me what she does. (Carer 19)

7.2 Recommendations for service providers and policy makers

Parent/caregivers were very clear in their advice for those who devise policies and provide services for individuals with disabilities and their families.

7.2.1 Joined-up service provision and valuing caregiver expertise

All participants agreed that joined-up thinking in service provision was important, as was equal partnership between service providers and caregivers.

Good communication between the various service providers. There's quite a broad range of them, there's health centres and educational psychologists but then there's also voluntary organisations as well, which in some respects have the greater expertise because they're set up by people who have this first hand experience and there's no substitute for that. Communication between everybody on an equal footing. (Carer 2)

Education and health services have to work together hand in hand. They cannot be separated. There is a big difficulty at the minute where one is under education and one is under health... Access to work is not only ramps and wheelchairs but also for walking disabled people who cannot drive, so access is a serious hindrance at times for disabled people to work. Access to work schemes should be increased. (Carer 8)

You have to look at the whole person, you just don't look at a person and deal with the health of this person, the education of this person, the domiciliary needs- they need to look at the whole picture. They have to have a holistic approach. They can't all be disjointed, where one hand doesn't know where the other hand is doing. People need a cradle to grave service and I think the second you have a diagnosis of any disability that's what you should have. I know that the reality is all about funding, always has been and always will be but I still think if they had a more joined up approach they could save money because they would have a service that fits, and not all these bits and pieces. (Carer 17)

The advice to service providers was to treat parent/caregivers with respect, not necessarily seeing them merely service users, but as a source of help and support for other parent/caregivers in similar situations. Parent/carers saw themselves as customers rather than service users.

Please appreciate that we are human beings and that we do have a life outside caring and that there may be other family members, not just necessarily siblings and partners but the bigger picture, like my parents and [husband's name] parents and we are juggling a lot of balls up in the air. We might not be in full time employment but our job is just as difficult and we need to be given a bit more notice about interviews and whatever, we are not a number just stuck there doing nothing while her daughter's at school. We try and fit in, in our spare time and our spare time is limited because we can't get [name] a key at three o'clock, 'Well, go in and let yourself in and I will be home at five'. (Carer 16)

See parents as a resource. We have gone through all the very worst our children can throw at us and we have come out the other end with hopefully with some strategies that might be applicable in other situations. See parents as a resource that is available to them. (Carer 15)

How do you hear the grassroots experiences in a way that impacts on the policies you write? At a training meeting the other day I heard that the time taken for research to input into the real world is around 18-years, far too long! How do they measure the policy they come up with? How do end users perceive it? How do they ensure meaningful engagement with their customers? Really to me often policy doesn't make it to the ground because

middle management block it, if money isn't targeted effectively it gets blocked or squandered. (Carer 3)

7.2.2 Information sharing

Parents felt that information was not always easily accessible, and that this was something that should not be difficult to improve.

A unit that dealt with everything, not just benefits, things that you can access...should it be respite, should it be a holiday, funding from some kind of support group, what groups you can go into, what group your child belonged to, when they meet, how often they meet, that would have been another outreach for [name], and if there had been a group that he could have fitted into... things aren't signposted enough to let the people know. (Carer 10)

7.2.3 Awareness and training in disability issues

Parent/caregivers advised that awareness, training, and individually tailored approaches should be at the forefront, including efforts to achieve appropriate early behavioural intervention, schooling, day-care, employment, and respite.

Training in disability, more proactive engagement with potential employees with disabilities, training for interviewing. A major employer noted that in 35 years he had never had anyone with autism present at interview, and one interviewer noted that they had had someone run out of the interview. Making interviews accessible is very important. (Carer 3)

Schools need to open their eyes are realise there is a big problem out there, especially in relation to autism. They really need to get their act together and start training teachers when they are in teacher training college, that they will come across children with disabilities of some form or other and I think they need to have a good knowledge of what makes these young people tick. I think that early intervention does help and if children are in mainstream schools they should be getting the help and understanding that they need and unfortunately at the moment they are not and are being failed, very badly. (Carer 17)

7.2.4 Flexible thinking around service and policy decisions

Parent/caregivers felt it was important for both service providers and policy makers to be more flexible and open to change in their thinking.

I think the Trust have to think outside of the box once in a while, to individually use their care, what suits one family won't suit another family, to look at the individuals as people and to be imaginative and to be challenged sometimes to change their minds (Carer 13)

I think sometimes a lot of support is very cheap, it doesn't always have to be about money. Very much, money can support and help in a certain way, there is a lot of other stuff there that is available that doesn't cost money, it costs nothing more than a little bit of organisation. Letting people know - here is a group of parents that are able to tell you what our children need, what we found useful, what we would have liked to have at an earlier stage - keeping on their back until they do it. (Carer 15)

The things that are important are peoples' lives. Be up there, and make the right decisions and listen to people. People are always up at Stormont lobbying for all sorts of reasons, listen to them, don't just give them lip service- just listen to them and maybe you will hear something worthwhile and do something about it. (Carer 17)

These recommendations from parent/carers, in their own words, bring to a close the data analysis sections of the report, and in the following sections, we draw together the key findings and make recommendations for future service provision.

Section 8: Discussion, summary and key findings

In order to inform both childcare and ageing policy and practice, the study presented in this report addressed the following research question: ***What are the main childcare issues for sons/daughters with a disability across the lifespan as they and their main caregivers grow older?***

In total 51 participants were either interviewed individually (20 parent/caregivers and 13 service providers) or took part in focus groups (9 parent/caregivers and 9 young adult service users with disabilities). The age range of parent/caregivers who took part in individual interviews (mean age 49.6 years; range: 32-78 years) and the age of their sons/daughters with disabilities (mean age 18.6 years; range: 3-53 years) represented the full lifespan. Parent/caregivers who took part in the focus group cared for younger children (mean age 4 years, range 2-9 years), and service users who took part in the focus group were young adults (mean age 23.5 years, range 19-29 years). Participants for this study were recruited from all over Northern Ireland, representing all Health and Social Care Trust areas, and representing a gender mix and an urban/rural ratio that was similar to general population trends.

The following sections will draw together the strands of information from all participants and discuss the major findings in a series of themes. While the questions were designed to have a common thread in all formats, there were situations where certain areas could only be covered in depth in individual parent/caregiver interviews; due to the sensitive nature of some of the topics (such as family finances and personal relationships) disclosure in the group format would not have been appropriate and for the service providers, such information about clients would have been confidential. Where key findings which informed our recommendations were identified, we have highlighted these in bold.

8.1 Home and family life

In general, parent/caregivers reported that family relationships with their partners, other children, and their own parents were affected by long-term care giving. Although this was not always negative, there was a higher likelihood of divorce or

feelings of neglect of siblings. Parent/caregivers had less time to pursue their own leisure interests, and the majority would like to spend more quality time with other members of their family.

8.2 Family health and wellbeing

8.2.1 Parent/caregivers

Parent/caregivers who took part in individual interviews highlighted a number of health related issues. First, in some instances they themselves were coping with an illness or disability, and the number of carers so affected was likely to rise with age; currently 41% of the Northern Ireland population aged from 60-74 years have a disability or disabilities, rising to an average of 60% among those aged 75 upwards (NISALD 2007, 19). Second, they were twice as likely as the general population to have poor psychological health, reflected in their high GHQ-12 scores and this is in line with other studies (Parish et al., 2005; Keenan et al, 2007; Dillenburg & McKerr, 2009a). The strategy for ageing (OFMDFM, 2007) aims to ensure that 'age related policies and practices create an enabling environment, which offers everyone the opportunity to make informed choices so that they may pursue healthy, active and positive ageing' (p.13). This should take account of the fact that individuals who have past the default retirement age may well continue to carry out caring responsibilities for their sons and daughters. In fact, caring responsibilities may even increase with age, for example, if someone has to support an ageing spouse in addition to a son/daughter with disabilities. Obviously a highly individualised approach to families' needs is required as the household grows older. **In particular older parent/caregivers drew attention to what they saw as the inequalities of ageing, where despite the fact that their caring roles did not lessen, their entitlement to Carer's Allowance was removed. The subsequent reduction in income was not met by retirement pension, even with the carer's premium. In addition, the fact that many carers of all ages did not receive a Carer's Assessment or knew that they were entitled to one, means that changes in circumstances will not be met by a timely response in terms of services.**

8.2.2 Sons and daughters

As well as their primary disability, over half of sons and daughters of interviewees (52.7%, n=10/19) had at least one other condition, including epilepsy and mental

health disorders. Two of them had other ongoing unrelated medical problems and a substantial proportion had behavioural and communication problems which caused difficulties in accessing services and support.

A high proportion of respondents had children with an Autism Spectrum Disorder (ASD) although no autism-specific voluntary groups had been approached when recruiting participants. It is known that the numbers of children diagnosed with autism has been increasing steadily and for Northern Ireland this now stands at 1 in 100 of the school population, higher than any other childhood disability (McConkey 2010). Although no definitive figures are available, it is likely a similar proportion is to be found in the adult population. Autism was not targeted as a disability in this study, but no one who met the inclusion criteria and volunteered was rejected. The convenience sampling (Robson 2005) therefore reflected the high prevalence and visibility of individuals with ASD in the community. Although it might be the case that this skewed the findings to some extent, most of the issues identified by respondents in this study are relevant to other conditions and generally present barriers to accessing services. Clearly, primary diagnosis alone does not determine the overall outcomes for sons and daughters with disabilities.

8.3 Financial aspects of well-being

Parent/caregivers were less likely to be in full-time employment than the general population, and thus were more likely to be worried about financial provision. Although financial matters were not directly discussed with the Focus Group parents, only three of the nine parents were in work. Two parents worked part-time, and one worked full-time but expressed concerns about being able to continue due to uncertainty about accessing childcare provision.

In terms of government policy, both the Anti-Poverty and Inclusion strategy (*Lifetime Opportunities*, OFMDFM, 2006) and *Improving Children's Life Chances* (OFMDFM, 2011) stress the need to target support and interventions which increase opportunities for children and young people to gain skills and knowledge. Our findings confirm that for adults of working age, 'enhancing childcare and addressing economic inactivity' (OFMDFM, 2006, p.45) are targets that would impact positively on the lives of both parent/carers and their adult sons and daughters.

This could in part be addressed by more efficient targeting of existing benefits and services. Many parent/caregivers did not receive enough information about available support, that is, they were not aware of statutory carer assessments or confused Disability Living Allowance (DLA), based on assessment of person with disabilities, with Carers Allowance, based on assessment of caregivers. A recent report by the Patient Client Council noted that ‘42% of parents, carers and family members said that they had never heard of a Carers Assessment and some of those who have had an assessment carried out are unsure that it had made any difference to their respite provision’ (2011, p.4). **Our research confirmed this and identified that parent/carers would like to have opportunities to seek employment and training, but the lack of appropriate care and sitting services tailored to their family circumstances made this difficult or impossible.**

Of the young adults who were service users, one young man had a full-time job, but for most, their weekday occupations were a combination of activities, for example a number of part-time jobs, a part-time job and a college place, or a daycentre with a work placement. While the service users were ambitious about gaining further skills and qualifications, it is likely that this will involve yet more input from parent/carers in arranging courses, placements and transport. Where placements break down or in coping with day-to-day problems, parents feel that they have to be available and this is a barrier to their full economic activity. **We recommend that the pastoral and practical care responsibilities for young people and adults with special needs should be developed within colleges, training centres and places of employment to shift the balance of this responsibility to the service provider rather than the parent/carer.** This will mean a much more tailored approach to all provision, with the individual’s needs clearly identified, in consultation with the service user and his/her parents, and strategies in place to address these before the placement begins.

8.4 Care and support within the family

Parent/caregivers are the main managers and ‘organisers’ of services and support for their sons and daughters. Even among the families with young children, support from other family members was limited because of the child’s special needs. In their recent study, Employers for Childcare (2011) found a strong reliance on grandparents as

childminders, but in our study, which adopted a lifespan perspective, grandparents who might once have been a valuable source of advice and assistance were too frail to offer support or no longer alive. Siblings were in general supportive of brothers and sisters with disabilities, and helped around the house, but parents were anxious about directing their other children into the role of primary carer. A previous study showed that this aspect worried older carers in particular (Dillenburg & McKerr 2009a).

When the young service users were talking about their leisure and employment activities it was clear that their families were a valuable resource in terms of personal support. They encouraged their sons and daughters to achieve and in some cases, e.g., a young Special Olympic athlete, to excel. Families also initiated and maintained the networks of social, leisure and employment activities; transport is a major issue here, a point picked up also by parent/caregivers in individual interviews. When at home, all the focus group participants used modern technology extensively for entertainment and social networking, and this was reported by parent/caregivers for the majority of their sons and daughters. Clearly, young adults with disabilities are 'internet literate' and use it extensively. **Service providers should make more creative use of modern technology to gather information to shape services quickly and be responsive to service user needs. IT should also be used to 'sign-post' activities and services through interactive directories.**

8.5 Care and support outside the family

In general, parent/caregivers appreciated support from professionals and from other parents of children with disabilities, requiring as much information as possible, as early as possible, and looking for long-term sustained commitment to services, rather than once-off or short-term treatments. They were ambitious for their sons/daughters (Lamb, 2009) and were very selective regarding services, with respite ('short breaks') and day-care being the most important services. When selecting and using services, parent/caregivers worried mainly about safety and security, staff sensitivity to individual needs, and flexibility of arrangements. They relied heavily on voluntary sector services and informal care arrangements. Most services came with a financial cost, particularly for adults; the only service that was entirely free for all service users was adult day-care.

Young adults with disabilities expressed their appreciation of what parent/caregivers did for them and found living at home a positive experience. They were ambitious and articulate and had strong and well-founded opinions. The young adults in the Focus Group wanted as much independence as possible, living lives that were similar to other young people their age, such as having relationships, travelling, working, taking part in sports, and learning to drive a car. They enjoyed respite and short breaks and holidays, clubs and a busy social life.

8.6 Accessing services

Social workers were the main contact point for service allocation, with the families of 10 sons and daughters (52.6%) citing them as their key contact. For others, a healthcare practitioner was their main contact for accessing services. Yet, over a quarter of families had no ongoing contact with health, social care or education professionals. Although most voluntary agencies accepted self-referrals, two of the statutory agencies involved with respite/short breaks only accepted referrals from a social worker. This effectively placed a barrier to accessing such services for those who have not been allocated a social worker, or where contact has broken down. **As respite was seen as a key service, access would be broadened by accepting referrals from other professionals (such as GPs, hospital consultants, Health Visitors, physiotherapists and psychologists) and self-referrals.**

8.6.1 Specific issues for carers of young children

Parents expressed concerns around safety and communication issues, in particular for children with poor language skills. The recent report on childcare and disability, *Childcare for All?* (Employers for Childcare, 2011, p.45), found that over one third of parents who did not use any form of childcare made this decision because ‘no childcare setting could meet their child’s needs’. Due to lack of available well-trained child minders willing to take on children with disabilities (especially autism) and also lack of knowledge about home childcare services, parent/caregivers could not avail of registered child minders and Home Child Carers.

The majority of parents of young children worried about the severe lack of good quality early interventions. Many opted for behavioural home programmes but had to fund these privately. A need for early intervention and a pro-active approach was not

exclusive to parents of children with autism, and all parents had made efforts to obtain the best start possible when their children were young, including one parent who had lived abroad to access what she considered was the most appropriate treatment for her child's disability.

Early intervention was found to be effective in reducing disruptive and distressing behaviours, and enhancing social and communication skills. It can increase the opportunities for children to participate more fully in social and educational opportunities and later on in their lives, and can mean more active participation in the social and economic life of the community. It also gives parents opportunities for social support and can relieve stress (Dillenburger et al., 2004). However, extensive international research shows that short-term eclectic intervention is much less effective than child-centred and individually tailored Early Intensive Behaviour Intervention (EIBI) based on behaviour analysis (e.g., Howard, et al., 2005). Generally, two years of EIBI is viewed as the minimum and most cost-effective requirement for a child with ASD (Motiwala et al., 2006). For example in Texas, Chasson et al. (2007) found that \$208,500 per child could be saved across 18 years of education. 'When applied to the conservative estimate of 10,000 children with autism the State would save a total of \$2.09 billion with EIBI.' In order to achieve similar savings and as recommended by the U.S. Public Health Service, Surgeon General (1999), **Early Intensive Behaviour Intervention (EIBI) should be made available to all families in Northern Ireland who wish to avail of it for their child.**

8.6.2 Specific issues for carers of older children and adults

Across the lifespan, parent/caregivers received decreasing levels of support from extended family as their sons/daughters aged. In terms of statutory services, a number of parents found the transition from Children's to Adult Services stressful and had concerns about the reduced level of service provision. For some this resulted in them seeking out alternative provision through voluntary organisations or parental contacts for their adult sons and daughters.

With increasing age, parent/caregivers worried more and more about the future, but 70% of them had not made firm future plans with regard to services or supported residential arrangements for sons and daughters, and a very similar finding was

reported in an earlier study on older (60⁺ years) carers in Northern Ireland (Dillenburg & McKerr 2009a). Reasons for this delay in planning varied from a lack of information about availability to an unwillingness to burden other family members with what could be seen as difficult decisions. **A co-ordinated effort should be made by HSC Trusts to signpost advice on matters of futures planning, e.g., issues around making Wills and nominating guardians, through existing Carer's services and use of the internet.**

8.7 Evaluation of services

Parent/caregivers generally felt they knew more about their son/daughters' needs than service providers, but believed that service providers did not always listen carefully enough. They felt that they should be viewed as consumers with a voice, who have high expectations for their sons/daughters and who educate themselves about quality of services. They were selective and did not feel that as far as services were concerned 'anything was better than nothing'. They were also ambitious for themselves and their sons/daughters, in terms of education and employment, basically wanting to lead a normal adult life. They wanted the same as every parent for themselves and for their children. **Future Governmental strategies regarding children, carers, older people, and poverty should continue to include high hopes and high expectations for all families and remain ambitious for all. This should entail joined-up links between these strategies to ensure a continuum of services across the lifespan.**

With regard to respite care, parent/caregivers worried mainly about safety and security of the placements, staff sensitivity to individual needs, and flexibility when selecting services. Providers generally had formal evaluation processes in place, usually based on a 6-monthly or an annual review. This method is not sensitive enough to determine the effectiveness of services and in general it should be easier to leave feedback so providers can respond promptly. One provider invited comments in a variety of formats- social networking sites, e-mails, web pages and a book available for written feedback after activities. These kinds of feedback systems are relatively easy to access and should be more widely adopted by service providers.

Listening, social support, and communication were some of the most valued services on offer. Service providers were concerned about cutbacks for services that were

already stretched, and acknowledged that the continued lack of joined-up thinking between children and adult services and between education, health, and social care remained problematic. Service providers felt that parent/caregivers were generally satisfied if and when they received good quality services, although accessibility could be limited. This finding was confirmed by a recent study on respite, where carers and users reported they would like greater availability and more options (PCC, 2011). In general, voluntary organisations were more responsive to changing needs, as they were able to tailor short-term funding proposals to meet the demand from service users and carers. The drawback of course was the sustainability of such projects. In the statutory sector, providers had innovative ideas particularly around respite services; respite is an area that has been targeted for enhancement in the current Action Plan for the Children and Young People's strategy (OFMDFM, 2008), but in real terms it would seem to have 'stayed the same' (PCC, 2011, p.3). **Experiences not only of parents and service users but also of providers of 'front-line' services should be considered more fully when HSC Trusts are considering how best to tailor and improve existing services in an economic climate of austerity.**

8. 8 Social and life skills

Acquiring social and life skills makes life much richer for sons and daughters with disabilities and their families, and these are essential for full social inclusion. Parent/care-givers expressed concerns about their sons/daughters' life-skills, related to mobility, communication, and challenging behaviour, all of which impact on their ability to form enduring and rewarding social relationships and take part in the types of leisure activities that other children and adults take for granted.

Appropriate educational provision was seen as extremely important by parent/carers of all ages and by all service users. Schools, colleges and day centres were seen as important not just for academic achievements but also for acquiring social and everyday life skills, such as cooking, personal hygiene and travelling on public transport. Many of the parent/caregivers felt their sons and daughters had not acquired appropriate life skills, either because these were not targeted, or because providing material items was viewed as the main concern by service providers.

Young adults with disabilities were keen to undertake further training and work experience to improve their skills. Improving work and training options and careers advisory service is a key point in for economic wellbeing in the Children and Young People's Action Plan (OFMDFM 2008). The Disablement Advisory Service offers a number of work and training schemes, accessed through Jobs and Benefits centres. Many young people with disabilities cannot access these services without support from their parents, which is difficult if parents are working or have limited access to transport. **Advice and information regarding careers and training should be available within schools during class time, on social networking sites, or through open evenings for parent/carers to allow for adequate time to prepare for the transition from school into adult training or employment.**

8.9 Experiences and implications across the lifespan: the bigger picture

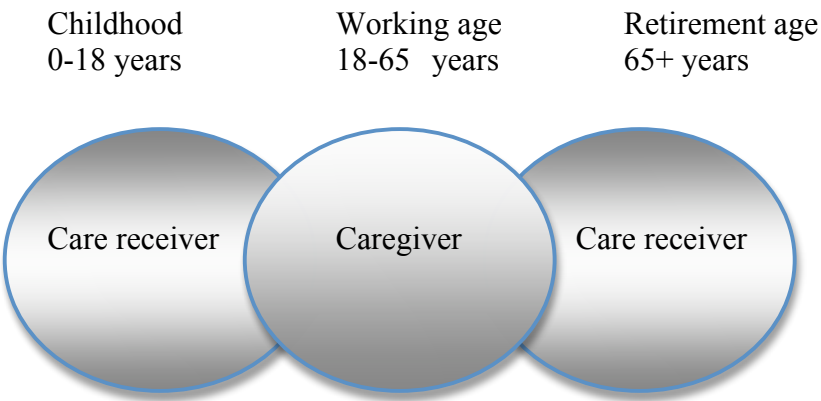
Parent/caregivers of son/daughter with disabilities are in it for the 'long-haul'. They experience first-hand the social, physical, and emotional cost of care giving. Ageing is an issue that worried all participants across the lifespan, although during the early years they focussed more on diagnosis and early intervention, while later in the lifespan they were more concerned with issues around employment, day-care and respite, often neglecting to make any plans for the future.

Across the lifespan, there are different ways to categorise age. Halcrow and Tayles (2008) distinguished between (1) chronological age, i.e., the time since birth; (2) physiological age, estimated from the biological changes in the body; and (3) social age, the culturally constructed norms of appropriate behaviour and status of individuals within an age category (p.190). While chronologically, parent/caregivers and sons/daughters with disabilities age, there are physiological differences and, of course, social age differences, leaving chronologically older parents caring for socially young sons/daughters.

Typically, during a lifespan caring roles change (Figure 1). During early childhood, everyone requires care, i.e., everyone is a care recipient. In most cases this role changes, and during adulthood people become caregivers for their own children, their ageing parents, or others. In most cases, this role is relinquished, as everyone grows

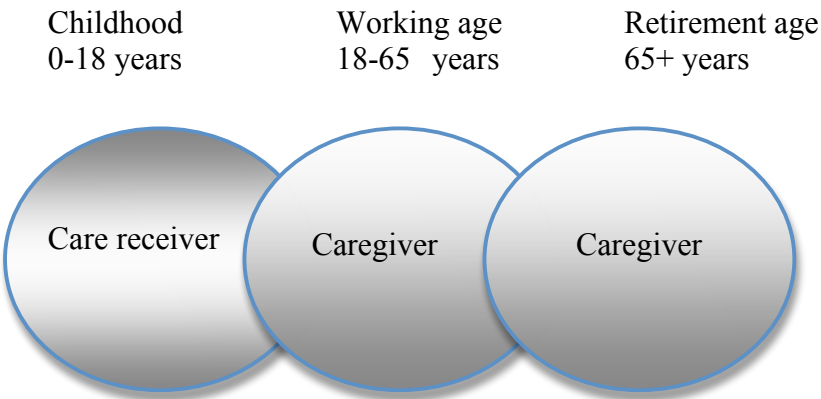
older and children become independent and parents may become recipients of care once again.

Figure 1: Schematic view of typical caring pattern across the lifespan



Life for parent/caregivers of sons/daughters with disabilities does not pan out this way. These parent/caregivers retain their caregiver role across the lifespan, as their sons/daughters are likely to continue to require care (Figure 2). In addition, research reported here exposes a dual predicament, because, as parent/caregivers age and may require care themselves, they cannot rely on their sons/daughters to be able to become caregivers. Consequently, they experience stress, poverty, and ill health.

Figure 2: Schematic view of caring pattern across the life span for parent/caregivers of sons/daughters with disabilities



Findings reported here show the main implications of caring for sons/daughters with disabilities across the lifespan.

8.10 Accessing care outside the home

During the very early years, services such as pre-school playgroups and day-care (0-4+ years) can be difficult to access for children with disabilities. In order to make this easier, these services need to be flexible and fit into each child's day, offering morning, afternoon or all day sessions. This would allow the child with disabilities to mix with typically developing children, and thereby facilitate inclusion within the wider community. The environment in pre-school provisions may need to be tailored differently for a child with special needs, and staff would need to have both generic and specific training. In addition, relatively small staff-child ratios are required.

Registered childminders are commonly used for typically developing children aged 0-12 years of age and allow parents to be integrated into the labour market. At the moment, this is not the case with children with disabilities and their parents. For childminders to become a resource for these families, the maximum numbers of children a childminder cares for have to be reduced, depending on the child's needs, and compensatory payments need to be made to make up for economic loss caused by the restriction to lower numbers of children. Childminders also require appropriate training in order to enable them to deal with issues related to specific disabilities.

For typically developing school-age children, after-schools and breakfast clubs can provide a continuous and familiar environment, with minimal disruption for travelling between facilities. For school-aged children with disabilities, hours need to fit parent/caregivers' working day, either full-time or part-time. The advantage is that school staff have the required skills base. In addition, holiday schemes are required to cover out-of-term care. Decreased staff-child ratios compared to 'mainstream' facilities will mean higher costs, and new staff will require both generic and specific training.

For adult sons/daughters with disabilities, day centres have the advantage that they are usually free to the end user, can offer all day care for up to five days a week, and transport is usually provided. However, capacity is likely to be a problem as life

expectancy increases and more adult service places are required. This research affirms that adults with disabilities are ambitious for themselves and would prefer to enter the regular (or sheltered) employment market, so an increased range of work and education opportunities is required to meet increasing needs. This will require coordination between education providers, employers, and providers of health and social care.

Across the lifespan, respite and short breaks services are very important to give parent/caregivers a break from care giving and allow them to spend time with other family members or seek employment or training. Currently respite care works well as for some families, but it is less useful when it is offered only for a short, relatively infrequent period and is not flexible enough to meet family needs, i.e., when families have to fit in with the respite offered, rather than the respite fitting around family needs. Of course, if more adequate day-care were provided, or if adults with disabilities were more fully integrated into the labour market, there would be less demand. Respite services would be freed up and could be provided more flexibly. In addition, respite care needs to be supplemented by ancillary services across the life course, e.g. social groups, befriending services, life skills and independent living services. Where caregivers are happy to take on commissioning care services themselves, there should be more assistance with direct payments and more support in administration with less bureaucracy and raised awareness of entitlement around all disability benefits.

Staff training and information across all services need regular updating in order to ensure flexible services that meet the needs of these families. There should be a fully resourced individual plan for teaching life-skills that is ambitious and aims to decrease dependency on ageing parents. Placements for employment and education should be co-ordinated by professionals, rather than relying on parent/caregivers to be managers of their adult son/daughter's day.

Across the lifespan, what is required is a safe environment that parent/caregivers can trust, that is tailored to each son/daughter's needs, flexible, reliable and regular, with good communication between staff and home and with integrated service between child and adult services and between education, health, and social care. In England,

the recent Green Paper on Special Educational Needs reform (Department of Education 2011) has resulted in the 'Pathfinder' trials of a limited version of such a plan (from birth to 25 years).

8.11 Conclusion: Policy and practice

The child strategy promised 'the development of a policy for children with a learning disability, which will take account of the recommendations of the review into Learning Disability in Northern Ireland and the Equal Lives report. It was intended that this would be the blue print for the reform and modernisation of services for children with a learning disability' (OFMDFM, 2006, p. 60). However, the second three-year action plan (covering 2008-2011; OFMDFM, 2008) that was aimed to implement the children's strategy is overshadowed by an economic climate of substantial general cutbacks and imposed savings. 'In the period 2010-11, £3.6 billion will be spent on health and social care ... but efficiency savings of some £204 million will also be needed' (Health and Social Care Board and the Public Health Authority, 2010). Any recommendations arising from this research study will have to bear in mind the very limited availability of funds. However, much of what parents, service users and providers have told us has emphasised that 'inside' knowledge can often tailor and improve existing services and make them more cost-effective.

The study reported here showed that the reliance on grandparents diminishes across the lifespan. With less reliance on intra-family support, there is an increasing reliance on extra-family support. In particular, care provided with no additional cost to the family is important. This includes day-care centres and some respite care, but more importantly, young people as well as their families emphasised the importance of mainstream or sheltered education and employment for adult son/daughters with disabilities. This research showed that these young people were keen to join the workforce. However, the question is how well are mainstream employers prepared for this? This is a question for policy and training of potential employers as increasingly the skills of people with disabilities are recognised, e.g., specific skills of people with ASD, such as organisation of materials, mathematical skills, skills in precision and repetition.

This project has investigated the needs of parents/carers and service users across the lifespan, in conjunction with the experiences of a number of providers from both the statutory and voluntary sectors, often in considerable detail as they have informed us about specific areas in provision. The final section details summary recommendations based on this research.

Section 9: Recommendations to professionals and policy makers

Parent/caregivers want to get the best available life for their son/daughters. They are ‘ambitious’ for their sons/daughters (Lamb, 2009). In order to help them achieve this, the main recommendations from this research are as follows:

- 1. Parent/caregivers should be helped to find dependable peer support throughout the lifespan, with signposting for access to support groups through the distribution of regularly updated booklets and information on webpage directories. This should be achieved through the existing framework for carers’ support within Health and Social Care Trusts, and closely monitored by the Carer’s Co-ordinators.**
- 2. Encourage and empower parent/caregivers to self-determination, by listening carefully to individual needs and working in true partnership and treating parent/caregivers with respect. This is in line with DHSSPS *Priorities for Action* (2), which emphasises the importance of PPI (Patient and Public Involvement) and the engagement of HSC Trusts with both carers and individuals with disabilities (2010, 19). Providers should offer a range of opportunities for service evaluation as well as a regular formal review, and take up this more diverse range of feedback within carer/client/Trust fora; the results should inform the annual DHSSPS Priorities review.**
- 3. Cost-effective, evidence-based early intensive behavioural intervention (EIBI) should be offered to all children diagnosed with ASD and other developmental disabilities and early advice regarding futures planning should be provided routinely.**
- 4. Structures are already in place for parent/carer consultation in transitions between Children and Adult’s services in all HSC Trusts, and within Education and Library Boards for transition from secondary level schooling into employment, further and higher education. Extending this service to include information on futures planning would be timely, as would the compilation of a directory of resources such as charities and carer’s organisations which can offer appropriate financial and legal advice.**
- 5. View individuals with disabilities as valued family members who can and should lead a full and enjoyable life. Employers for Childcare (2011, p. 75) have identified the need for an integrated childcare strategy for children with disabilities/special needs. Recommendations from the present research go even further:**

there should be an integrated lifespan care and support strategy which draws in expertise from all agencies involved with disability services, parent/carers and service users.

6. **Deliver joined-up services across education, health, and social care (and Children's and Adult services) that utilise an effective two-way process of communication and exchange of information between professionals and caregivers. DHSSPS identify a 'whole life approach' as a priority in disability services, and also acknowledge the increasing importance of multi-disciplinary and multi-agency co-operation in service provision (Priorities for Action 2010-2011, p.37, p.45). Our research fully supports this approach. In addition, in order to ensure the effectiveness of these strategies there should be measurable outcomes of services and interventions and carer/client involvement. The need for detailed individualised measures of effectiveness should be built into all strategies.**
7. **Access to clear information on benefits, direct payments, carers' assessments and work support schemes should be available to all carers. While acknowledging that this involves input from a number of agencies, carer's services within HSC Trusts should ensure that key workers compile a summary of up-to-date information on disability benefits and services that they distribute effectively to clients.**
8. **When carers reach statutory retirement age and continue to carry out caring responsibilities, they should not be penalised financially by a change in benefit status. Many ageing carers did not receive a carer's assessment and as needs change with age, it is important to keep the carer assessment up-to-date. A full carer's assessment should be mandatory at regular intervals, especially once carers reach statutory retirement age.**
9. **For pre-school children, all registered day-care establishments (crèches, nurseries, playgroups etc) should have the equivalent of the Special Educational Needs Co-ordinator (SENCO)⁹ who would be responsible for ensuring staff training was adequate for special needs provision. To increase availability of childminding services, there should be compensatory payments to the provider, to cover the economic impact of looking after fewer children. Staff should receive appropriate training to enable them to deal with issues related to specific disabilities, and childcare qualifications (for example, NVQ and BTEC) should incorporate a substantial component that relates to disability.**

⁹ In schools, the SENCO is a teacher who is responsible for the operation of the special needs policy and co-ordination of services. For a full description of the role, see http://www.deni.gov.uk/the_code_of_practice.pdf, p. 6.

- 10. For school age children with disabilities, given that staff will already have an established skills base, in-school provision (such as Breakfast, After school and Saturday Clubs and Holiday Schemes) should be the major focus of any expanded childcare strategy.**
- 11. Colleges, workplaces and adult centres should put in place robust, individualised support systems that will both enhance the life-skills and the education and employment opportunities of adults with disabilities. This would transfer some of the most time consuming responsibilities from parent/carers, allowing improved participation in social and economic activities for carers and sons/daughters with disabilities.**
- 12. Both policy makers and practitioners should be knowledgeable about the most up-to-date, evidence-based, international best practice interventions to ensure that individuals with disabilities achieve their full potential across the lifespan. Professional development for staff should include regularly updated training courses on disability issues in general, on caring for children with disabilities across the life course, and on evidence-based interventions.**

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Glossary of abbreviations used in this report

BMA British Medical Association.

BTEC Business and Technology Education Council

CDSA Children with Disabilities Strategic Alliance.

CPN Community Psychiatric Nurse

DDA Disability Discrimination Act 1995.

DHSSPS Department of Health, Social Services and Public Safety.

DLA Disabled Living Allowance

ELB Education and Library Board.

GHQ12 General Health Questionnaire (12 questions)

HSCT Health and Social Care Trust(s).

KLT Kids Life and Times Survey

NHS National Health Service.

NVQ National Vocational Qualification

NILT Northern Ireland Life and Times survey

NISALD Northern Ireland Survey of Activity Limitation and Disability.

NISRA Northern Ireland Statistics & Research Agency.

OFMDFM Office of the First Minister/Deputy First Minister.

PCC Patient Client Council

SENCO Special Educational Needs Co-ordinator

YLT Young Life and Times Survey

APPENDIX 1: Information and consent forms

1. Outline information form for participants: service users and service providers

Summary of information on the childcare research project:

The working title of the project is 'Childcare issues for disabled children, especially with regard to caregivers as they grow older' (taking the term 'child care' to mean care for children of all ages, both in the home and outside it).

This project is funded by the OFMDFM/NISRA * and aims to find out about issues related to childcare/parenting a son or daughter with disabilities, especially as parent/carers themselves grow older. Recently we conducted research with older parents (60+ years) of sons and daughters with disabilities and we are now interested to hear from parents/carers of all age groups, and those who provide services for their children. We hope to learn much from parents, service users and those who provide services and be able to inform policy makers, professionals, and other parents about these important issues. The principal investigator is Dr Karola Dillenburger, of the School of Education at Queen's University Belfast, and Dr Lyn McKerr is the research assistant on the project. The Research Ethics Committee of the School of Education of Queens University of Belfast reviewed and approved this research.

If you have any further questions you can contact Karola at 028 9097 5985, or Lyn at 028 2954 1991. Alternatively, you may wish to email us at:

k.dillenburger@qub.ac.uk or

l.mckerr@qub.ac.uk.

We look forward to hearing from those interested in taking part.

2. Participant Information Sheet (parent-carers and service providers)

School of Education Queen's University of Belfast Research Project

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Childcare issues for disabled children, especially with regard to caregivers as they grow older

People who are caring for children with disabilities often are under tremendous stress and worry about child care issues. This research aims to find out about childcare issues for a child with disabilities and their parents especially as they themselves grow older. We hope to learn much from parents and stakeholders and be able to inform policy makers, professionals, and other parents about these important issues.

You have been chosen to take part in the study either because you are caring for child with disabilities yourself or you work in an agency that is concerned with childcare issues of children with disabilities and their caregivers.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the service you receive.

If you decide to take part you will either be interviewed by a member of the research team or take part in a focus group and asked to complete a brief questionnaire. The interview/focus group should not take longer than 45-60 minutes and researcher will be available to help with the questionnaire.

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that leaves the agency will have your name removed so that you cannot be recognised from it. Once the study is completed results will be presented in written papers and in oral presentations. Please let us know if you would like a copy of the results.

The Research Ethics Committee of the School of Education of Queens University of Belfast reviewed and approved this research.

If you have any further questions you can contact me,
Dr Karola Dillenburger, at 028 9097 5985 or email me at k.dillenburger@qub.ac.uk
Thank you very much for participating in this study

3. Participant Information Sheet (service user Focus Group 1)

**School of Education
Queen's University of Belfast
Research Project**

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

This research aims to find out about care issues for a child or young person with disabilities and their parents especially as they themselves grow older. We hope to learn much from parents, young people and service providers, and be able to inform policy makers, professionals, and other parents about these important issues.

You have been chosen to take part in the study because you are a service user and you belong to a group that is concerned with disability issues.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the service you receive.

If you decide to take part you will be involved in a focus group, where your views on care and leisure provision will be discussed. The focus group should not take longer than 30 minutes.

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that leaves the agency will have your name removed so that you cannot be recognised from it. Once the study is completed results will be presented in written papers and in oral presentations. Please let us know if you would like a copy of the results.

The Research Ethics Committee of the School of Education of Queens University of Belfast reviewed and approved this research.

If you have any further questions you can contact me,
Dr Karola Dillenburg, at 028 9097 5985 or email me at k.dillenburg@qub.ac.uk

Thank you very much for participating in this study

4. Consent form- on Queen's University Belfast headed paper

CONSENT FORM

Title of Project: **Childcare issues for disabled children, especially with regard to caregivers as they grow older**

Name of Researcher: Dr Karola Dillenburger

Please initial box

- 1.I confirm that I have read and understand the information sheet ☐
for the above study and have had the opportunity to ask questions.
- 2.I understand that my participation is voluntary and that I am free to ☐
withdraw at any time, without giving any reason, without services or
legal rights being affected.
- 3.I agree to take part in the above study. ☐

Name of Participant Date Signature

Name of Researcher Date Signature

1 for participant; 1 for researcher

APPENDIX 2: Interview and Focus Group Schedules

1. Interview schedule: Service Providers

Name/ID:

Organisation:

Position:

Date:

1. What services do you offer/arrange for families of children with a disability?
2. How do families contact you and do you offer/arrange services to individuals with any or all of the following
 - a. learning disabilities
 - b. physical disabilities,
 - c. behavioural issues
 - d. sensory impairments
 - e. mental health issues
 - f. other disability, such as
3. Have you received any formal training for your work?
4. What age ranges do you offer/arrange these services for?
5. How many individuals currently use your services?
6. Are these services provided on a regular basis, and if so is this
 - a. Daily
 - b. Weekly
 - c. Annually
 - d. Other (please give details).
6. What is your geographical catchment area?
7. How are the services you offer funded – e.g. by Trusts/parental contributions/grant aid/ voluntary group / other?

If there is a combination, what is the proportion of funding from different sources making up the total?
8. How do you think the main carers perceive the service(s)?
9. How do you measure this?
10. Do you have any independent evidence e.g. surveys?
11. How do you think the service users perceive the service(s)?
11. Again, how do you measure this?
12. In your opinion, what are the major positive factors for the families in the service(s) you provide?
13. How do you think the service(s) could be improved? Have service users or carers made any suggestions for improvement?

Thank you for taking part in this interview. We will contact you again when the research is complete and if we have an official launch for the report we hope you will be able to attend.

2. Interview schedule: Service Users (parent-carer individual interview)

Name /ID

Carer M/F

City/Town/Village/Rural household

Location.....

A. About you and your family situation in general

1. How long have you lived here?
2. Why did you choose to live in this area? (*Prompt if necessary* e.g. close to relatives, available public housing, close to suitable schools or hospital).
3. What is your working situation at the moment?
full-time /part-time/not in paid employment/ a student or in training (*for both interviewee & partner if applicable*)
4. Are there any issues around your own health that affect the care of your child?
5. How many people live in the household and what are the ages of dependent children? Do any other adults, e.g. a grandparent, live with you?
6. Which best describes your position as a carer?
 - a. Main
 - b. Shared – with whom?
 - c. Only
7. Would you mind telling me your age and that of your partner if applicable?
Alternative for those who would prefer to give age ranges
20 years or under
21-30
31-40
41-50
51-60
61-70
Over 70
8. Are you married/nor single/single never married/divorced/widowed?
9. Would you say your child's disability has affected your relationship with your partner? If so, can you explain in what way your relationship is affected?
 - a. Financially
 - b. Emotionally
 - c. Socially (including leisure and holiday times)
 - d. Other, such as
10. Would you say your child's disability has affected your relationship with your family? If so, can you explain in what way your relationship is affected?
 - a. Financially
 - b. Emotionally
 - c. Socially (including leisure and holiday times)
 - d. Other, such as
11. Are you a member of any groups or organisations which relate to your child's disability (*prompt if necessary* e.g. Mencap, Carers NI)

B. About your child/ren with disabilities

12. What age is/are your child/ren with disabilities
13. What was/were the diagnosis/es and at what age did your child/ren receive this?
14. Are any of the following factors an issue for your child/ren when at home (please give some further details)
 - a. Health
 - b. Mobility
 - c. Behavioural
 - d. Sensory issues
 - e. Diet
 - f. Communication skills
 - g. Mental health issues
 - h. Other, such as?
15. What arrangements do you make to cope with these issues?
16. Does your child currently attend mainstream or special pre-school/ school /day centre/ work/ training/college?
17. Was this the pre-school/ school/centre/work/training/college placement of your or [adult child's] choice?
18. How was that arranged? (*Prompt if appropriate*, e.g. Health Visitor, Social Worker). What was helpful and what was a problem with this?
19. Is it close to home, and how does your child get there?
20. Do you feel the pre-school/ school/day centre/training/ work/college placement is assisting your child's development in
 - a. academic areas such as reading, writing, maths skills
 - b. social skills
 - c. life skills (*prompt if appropriate*, e.g. personal hygiene, eating out or in a dining hall, cooking, dressing, travelling on public transport, visiting museums or cinema etc)
21. Please tell me how your child/ren spend the time when they are home from pre-school/school/work, day centre or training

C. About the support provided for your child/ren

This section deals with any services or support your family may receive while caring for your child, including advice, home improvements or adaptations, health and social care.

22. If you have access to support services, who is the main point of contact for you?
23. Are there any special adaptations at home to help with your child/ren's disability?
 ** If 'No', go to question 24**
24. Are these adaptations helping, and if so, is this the way you had hoped? If not, what are the problems?
25. Is there any support (e.g. domiciliary care/ social work/carer's assessment /advocacy) provided for the family &/or child/ren?
 If **yes**, what is helpful or a problem with your support?
26. If you have older or younger children as well as [name of child/ren with disability] do they help with [name of child/ren] or with household jobs?

If **yes**, what do they do?
How often, and how long for?

27. Have you accessed any childcare (*care or sitting*) services in the last 12 months? If so, can we fill in the following table with some details?

Service	What scheme?	How long for?	What was helpful	What was problematic	How was it arranged	What did it cost
Respite etc.						
After-school club						
Holiday schemes						
Informal care						
Nanny						
Service	What scheme?	How long for?	What was helpful?	What was problematic	How was it arranged?	What did it cost?
Registered childminder						
Unregistered childminder						
Daycare-pre-school						
Daycare-adult						
Other						

****If 'No' to all the above, go to question 29****

28. If you used childcare services in the last 12 months, were you satisfied with:
- the quality of the care
 - the duration of the care
- and how would you say the situation benefited you and your family?
29. For those not using any of the childcare services in q.27 *
- I want to ask you a bit more about why you are not using child care/respite services. Which, if any, of the following did you find were the main issues with accessing childcare outside the home?
- Need special equipment/training for carers,
 - Not flexible enough to cope with family situation,
 - Not at suitable times,
 - Not easy to arrange,
 - Not always an enjoyable experience for child/ren,
 - Too expensive
 - Not confident of quality of care
 - Refused a place on a scheme (please give details)

- i. Would always prefer to look after my child/ren myself
 - j. Other – please give details
30. Are any of the following factors in your child/ren's disability an issue in accessing appropriate childcare/ *respite/work/day centre/training/college* services
- a. Health
 - b. mobility
 - c. Behavioural issues
 - d. Sensory issues
 - e. Diet
 - f. Communication skills
 - g. mental health issues
 - h. Other, such as?
- ** If none, go to question 32****
31. If so, have you had any help with these issues? What kind of additional help would be most useful to you?
32. Have you ever had any training in dealing with any of the above issues? If so, can you explain a bit about it?
33. What would be the ideal system of childcare/ *support* for your individual family, both inside and outside the home?
34. If you had the 'ideal system', how would this improve your quality of life e.g. would it allow
- a. More time to spend with other children in the family
 - b. More time to spend with other family members
 - c. Opportunity for parent/carer to enter employment
 - d. Opportunity for parent/carer to undertake study or training to gain extra skills & qualifications
 - e. More time to spend on leisure pursuits- e.g. sport/cinema/going out/travel
 - f. Other, such as....

D. Financial aspects

35. Do you [*or your child*] receive any of the following benefits or allowances because of your child's disabilities?
- a. DLA- at what rate (Low/Middle/High), and does this include the care and /or mobility component ?
 - b. Carer's allowance
 - c. Direct payments
 - d. Other
36. Have you asked for help in applying for any benefits, and if so, what happened?
37. Have you been refused any of these benefits, and if so did you appeal? Can you explain the process you went through?
38. If you have not applied for benefits, what has prevented you?
39. Would you say you worry about family finances
- a. Not at all
 - b. Occasionally
 - c. Fairly often
 - d. Very often
 - e. All the time

E. Social activities/ opportunities for your child now and in the future

40. Has your child missed out on local activities because of problems around their disability (e.g. summer schemes, after-schools clubs, school trips, youth groups/ leisure interest groups)?
41. If so, has this been because
 - a. Specialist support was not available
 - b. It was too expensive
 - c. Transport would be a problem
 - d. There were health issues around your child's condition
 - e. There were behavioural/emotional issues around your child's condition
 - f. Other?
42. Do you think there has been a shift in awareness or attitudes towards children and young people with disabilities
 - a. Among the general population
 - b. Government organisations (e.g. such as Health Trusts, Education and Library Boards)
43. What do you feel are the issues about caring as you and your child grow older?
44. Have you made arrangements for the continuing care of your child/ren as you grow older? * If so, are these
 - a. Financial
 - b. Formal arrangements e.g. a care plan or a legal document
 - c. Informal arrangements- family members have said they will help
 - d. Other, such as
45. ** If not, what would be the main reasons?
46. Finally, given your own experiences in caring, what would be your recommendations
 - a. For other parents
 - b. For schools/ *day or training centres/workplaces*
 - c. For other service providers
 - d. For policy makers?

Thank you very much for taking part in this interview. We will contact you again once the research is complete and if we have an official launch for the final report we hope you will be able to attend.

3. Interview schedule: Service Users (young adults Focus Group)

Focus Group

Aims: We want to discuss some of the services provided by government and by groups like Mencap for young adults like you.

Guidance for how this works: We hope you will feel you can take part fully and we will respect the comments of everyone round the table. There are no right or wrong answers, and please feel free to join in with your opinion. What you say here is important for our research, and we may quote certain things that you say in the final report but you will not be named or identified. I will be asking questions and making sure that everyone has a chance to put their point of view, and Lyn will be taking notes and recording answers.

Method of recording: Voice recorder, flip chart & note taker

Introductions/ 'ice-breaker' questions

1. I want to ask you all in turn if you would tell us your age, and tell us whether you live at home or in independent living.
Who else lives there?
2. Can we talk a bit more about where you live and how that works out for you?
At home, who looks after you and helps you with things you need help with?
What kinds of things do you do when you are at home? (e.g., watch TV, read, play with brother, help mother, etc)

Service use

3. I want to ask you now if you have ever used the 'short break' or respite service
Where did you go?
How long did you go for?
How many times a year did you go, and when?
Did you find it useful?
Was it enjoyable?
What do you think would have made it better?
4. Have you used a youth group or club in the last year and who provided that?
Where did you go?
How often did you go?
How long did it last?
Did you enjoy it?
Again, what do you think would have made it better?
5. Who in your house makes the decisions about holidays, short breaks and clubs?
6. Did you go to a training or day centre in the past year?
Where do you go?
How often do you go?
How long does it last?
Do you enjoy it?
Again, what would have made it better?

Thank you very much for taking part in this focus group: when the research is complete we will contact you again and if we have an official launch for the report we hope you will be able to come to it.

4. Interview schedule: Service Users (parent-carers Focus Group)

Focus Group

Aims: We want to discuss some of the services provided by government agencies such as Health Trusts and by voluntary organizations for parents like you, caring for their child or children with disabilities.

Guidance for how this works: We hope you will feel you can take part fully and we will respect the comments of everyone round the table. There are no right or wrong answers, and please feel free to join in with your opinion. I will be asking questions and making sure that everyone has a chance to put their point of view, and Lyn will be taking notes and recording answers. What you say here is important for our research, and we may quote certain phrases that you use in the final report but there will be nothing published that can identify you or your child.

Method of recording: Voice recorder, flip chart & note taker

Topics

Introduction/ 'ice-breaker' questions

You may not automatically think of yourself as a carer, but in fact by caring for your child with disabilities, you are one of an estimated 185,000 people Northern Ireland (according to Carer's NI) who look after a family member or friend with disabilities. The government funds a variety of services for people caring for their children across the life course, so your experiences and your views are important.

7. I want to ask you all in turn if you can give us the ages of your child or children with disabilities, their diagnosis and the age at which this was received?
Which Health Care Trust provides your services?
Do you consider you are the main carer for your child or children?

Service use

8. Once you received the diagnosis, did you find access to specific support services straightforward? *For example, do you have access to advice from a social worker?*
Have any of you had a carer's assessment?
What was helpful in this process?
Were there problems with this process?
9. We'd like to talk a little more about the services you receive. We know that you are currently using an early intervention programme provided by a voluntary group, which also provides parent support.
How is it helping you in your role as carer for your child?
What do you think would have made it better?

10. Have any of you used a childminder (registered or unregistered), nanny or daycare for your child with disabilities in the last 12 months?
If so, what was helpful or problematic about it?
If you haven't used a childminder, what would be the reasons you didn't?
What is it about your child's condition which might affect your decision to use a service like this?
11. We'd like to talk about the 'short break' or respite service. What has been your experience with this?
If you use it, how long for and how often?
Was it enjoyable for your child?
What do you think would it have made it better?


If no-one has used this service, can you explain why not?

12. If you feel comfortable talking about it, we'd like to ask how your child or children's disability has made a difference to family life.
Firstly, do you feel it has altered the things you can do as a family and if so, in what way? *What has been the social/emotional impact?*
Has it had a financial impact? *Have you or your partner had to leave work?*
How do you find access to the benefits system? *Are you aware of the range of benefits which may be available for those caring for a child with disabilities?*
Have you asked for help in applying for benefits, and if so what happened?
Has anyone ever been refused benefits or had to appeal a decision?
13. What services do you feel would improve the quality of life for your family?
e.g. *early intervention/domiciliary support/short breaks/qualified childminder/advice service...*
If you had the 'ideal' system for your situation, what would it allow you to do?
e.g. *consider taking up or increasing your hours of employment*
consider further education or training
have more time for other children/partner/family members
have more leisure time
other, such as
14. We appreciate that your children are very recently diagnosed, and are still very young, but at what stage do you think you might begin to plan for their longer-term future? What do you think would be helpful in going about this?
15. Finally, what advice do you think carers can give government organisations regarding support services for parents caring for children with a disability?

Thank you very much for taking part in this focus group: when the research is complete we will contact you again and if we have an official launch for the report we hope you will be able to come to it.

APPENDIX 3 Example of DLA letter

 **DSD**
Department for
Social Development
www.dsdni.gov.uk



SOCIAL SECURITY AGENCY

 **INVESTOR IN PEOPLE**

Your reference is _____
Please tell us this number
if you get in touch with us

Disability & Carers Service
Castle Court
Royal Avenue
Belfast
Northern Ireland
BT1 1HR
Phone 028 90906182

Our fax number 028 90336557
Website www.dsdni.gov.uk

Date 04 May 2011

Dear _____

ABOUT THE AMOUNT OF MONEY WE PAY YOU

You are dealing with a claim for _____. Remember
that the information in this letter is about them.

**Please keep this letter safe, as it is proof of your
entitlement to benefit.**

The amounts of most benefits have been increased. This means
that your Disability Living Allowance will go up from 66.75
to 68.85 a week from 13/04/2011.

You are entitled to:

middle rate care component for help with personal care from
16/02/2010 indefinitely

lower rate mobility component for help with getting around
from 16/02/2010 indefinitely

How much money we can pay you

From and including 13/04/2011 you will be paid:

For help with personal care

For help with getting around

The total each week is

How you will get your money

We will pay _____ into your account.
This is for your Disability Living Allowance from
13/04/2011 to 10/05/2011.
This is the first payment which includes the increased rate.
The increase is only for the period from 13/04/2011.
Your future payments will be £ _____